



## Director's Message: Connecting & Expanding Our Presence

As we near our competitive renewal application next year, we are working to expand CPIC's presence. As a group, we will meet during IDWeek on October 14<sup>th</sup> to discuss progress on current research protocols, how to expand our portfolio for the next round of RDCRN funding, and to hear about the research of our most recent past pilot recipient, Dr. Carol Kao. IDWeek will also provide an opportunity for networking with our CPIC Scholars (one of whom, Dr. Patricia Pichilingue Reto, has a poster on a novel antimicrobial stewardship program intervention) and for highlighting presentations done by CPIC-affiliated faculty. Dr. Mark Schleiss will present Minnesota's congenital CMV screening data as a "late breaker" abstract. This presentation will take place on Thursday, October 12 from 1:45-3:00pm in 254 AB. Additional information on Minnesota's first-in-the-nation CMV screening effort is described below. In addition, Javier Nishikawa and Amanda Evans are presenting posters on work related to our CPIC activities, so try to visit those as well. I'm excited about connecting with everyone at our upcoming meeting and am looking forward to an energizing discussion about CPIC's future!

Stay safe and well –  
David

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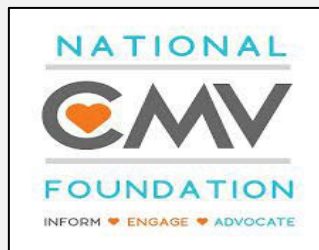
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## Important Happenings in CMV Advocacy

- The Minnesota legislature passed a law known as the [Vivian Act](#) in 2021. The law is named for Vivian Henrikson who was identified with congenital CMV (cCMV) shortly after birth. Her mother Leah, Dr. Mark Schleiss, and other parents of affected children introduced the idea for the bill. Among other things, the Vivian Act required a review of cCMV for possible inclusion on Minnesota's newborn screening panel. After much review, this was approved in February of 2022, making Minnesota the first state in the nation to screen every newborn for cCMV.
- In June of 2023, US Senator Richard Blumenthal, D-Conn., announced the [Stop CMV Act of 2023](#) to incentivize hospitals and health care providers to universally screen for CMV in newborns' first three weeks. The bill is pending while seeking a Republican co-sponsor, before being formally introduced in Congress.
- On Monday, 10/2, New York state began a one-year, \$1.36 million pilot funded by NICHD to test all newborns for CMV using dried blood spots as part of their newborn screening program. This is available to the approximately 220,000 babies born annually in the state.



## Protocol Status

- 1) The Neonatal EV Sepsis protocol is v3.0 (6/27/23) is active at 29 sites, with 33 subjects enrolled in the main study and 4 in the Arm (deceased subjects).
- 2) The Valacyclovir PK protocol v3.0 (8/9/22) has been activated at 7 sites. Others are encouraged to submit ICFs and site activation documents. It has 3 subjects enrolled, and 1 with PK data collected.
- 3) The Retrospective cCMV protocol v3.0 (3/24/23) is active at 3 sites, with 5 enrolled. NIAID wants this study completed by August 2025, so we need your help to get sites activated and enrolling. Submit tracked ICFs and local context documents and complete training ASAP.
- 4) The Letemovir PK protocol v1.0 (2/13/23) has been submitted to the UAB IRB and is under review. Sites have been selected and the site initiation visit is scheduled for November 9<sup>th</sup> from 9am-1pm via Zoom.

## CPIC Scholar Program Invites Applications for New Scholars

*The CPIC Scholars Program is open to interested fellows and early-stage faculty conducting mentored research related to congenital and perinatal infectious diseases. Diseases do not have to be one of the current CPIC protocols. Scholars may request CPIC funds to attend meetings or participate in a mini-sabbatical research experience. The application is brief. Visit <https://cpic.rarediseasesnetwork.org/funding-opportunities/scholar-awards>; contact Melissa McBrayer, Program Manager, with questions or for more information.*

## Administrative and Financial Updates

Our 3rd budget year came to a close this summer (9/1/21 to 8/31/23). All invoices for this period must be received by 10/30/23 according to the subaward agreement. UAB may be unable to pay any invoice received after this date. New subaward amendments for Year 4 (9/1/23 to 8/31/24) are in process at UAB. If you have any questions about invoicing for subaward agreements, please direct them to Sarah Dowdy ([sdowdy@uabmc.edu](mailto:sdowdy@uabmc.edu)).

Data Hosting Agreements Required for EV Sepsis and Retrospective CMV Studies – CPIC utilizes REDCap database services through the RDCRN's Data Coordinating Center at Cincinnati Children's Hospital Medical Center (CCHMC) for these studies. Check [here](#) to see if your site has an executed Data Hosting Agreement (DHA) with CCHMC. Questions about the DHA should be directed to [rd.dmcc@cchmc.org](mailto:rd.dmcc@cchmc.org).

## Links

[Rare Diseases Clinical Research Network \(RDCRN\)](#)



CPIC is supported by the UAB Central Unit located at:

The University of Alabama at Birmingham  
Children's Harbor Building, Suite 303  
1600 7<sup>th</sup> Avenue South  
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## Publicizing the RDCRN & CPIC Research

Dr. David Kimberlin, PI of CPIC, was recently interviewed by Peds Cast, a pediatric sub-specialist peer-to-peer podcast focused on research, innovative programs and advances in pediatric health care at Children's of Alabama. He used the opportunity to promote the RDCRN and to explain the importance of increasing treatment options for rare diseases. He also discussed the work done by CPIC and its predecessor, the Collaborative Antiviral Study Group. A link to the podcast and its transcript can be found [here](#).

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