



## Director's Message: RPPR Accomplishments

In our initial RPPR, submitted for the 7/1 deadline, we reported extensive involvement with the Data Management and Coordinating Center (DMCC) including their agreement to use our Neonatal EV Sepsis natural history protocol to pilot test how the Cincinnati Children's Hospital Medical Center IRB might serve as the single IRB of record for Rare Diseases Clinical Research Network (RDCRN) sites. We also worked with the DMCC to explore the possibility of developing and leading an International Congenital CMV Registry and to develop online content for the RDCRN website.

In addition, we agreed to process samples for the RDCRN Primary Immune Deficiency Treatment Consortium to assist with their study of CMV in neonates with severe combined immunodeficiency, and we shared our EV Sepsis Natural History protocol with the Phenylalanine Families and Researchers Exploring Evidence (PHEFREE) Consortium as an example of how to write a longitudinal natural history and outcomes study. Going forward, we will continue to work to add value to the Network.

Stay safe and well –  
David

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## COVID-19 Update

Though we are continuing to work on Consortium activities, as detailed in this eBrief, many of us are still working remotely at least part-time and connecting by Zoom or WebEx to communicate. We now have 14 sites with executed subawards for our Neonatal EV Sepsis protocol, with 4 activated to enroll and 10 having IRB pending. Fourteen other sites are still in the process of establishing their subawards.

After a slight delay related to COVID-19, we also posted our call for CPIC Scholars and Pilot and Feasibility Project pre-applications on May 22nd. We have requested full pilot applications from three individuals and continue to seek additional CPIC Scholars for our virtual training opportunities. We plan to have a group of CPIC Scholars and our inaugural pilot recipient named by September 1st. We also hope to begin enrolling subjects in our Neonatal EV Sepsis study soon, at least in areas that are less impacted by the COVID-19 pandemic.

