HANDOUT 1

January 2, 2020

Childhood Post-Infectious Autoimmune Encephalopathy (CPAE) Clinic Report

Dr. Richard Smith Marie Wilson Howells Professor and Chair Department of Psychiatry, College of Medicine Director, UAMS Psychiatric Research Institute University of Arkansas for Medical Sciences

On December 5 and 6th the new clinic was site visited by the leadership of the PACE foundation, Paul and Patricia Ryan. The foundation furthers and coordinates the work of a consortium of multi-disciplinary CPAE clinics of which the new Arkansas Children's Hospital (ACH) clinic will be the fifth in the nation joining the University of Arizona/Banner Health clinic in Tucson/Phoenix; UCLA, Stanford, and the University of Wisconsin. Three more clinics on the east coast are planning to join the consortium at which time the option of becoming a member of the consortium will not be an option. The ACH clinic is expected to draw patients and families from a multi-state region as well as potentially internationally.

During the site visit the Ryan's met with a group of family advocates/stake holders, UAMS leadership and Arkansas Children's Hospital leaders including UAMS Chancellor Dr. Cam Patterson, and ACH CEO Marcy Doderer at a reception, the Child Health and Communications leadership at the Arkansas Department of Health, the Communications leadership at ACH, members of the Governor's staff, met with the Co-Medical Directors of the clinic Dr. Raney and Veerapandiyan and UAMS leadership; toured the physical space of the clinic at ACH with Senator Hammer and Representative Warren; and met with ACH leadership including ACH CEO, Marcy Doderer at Children's Hospital.

The Ryan's discussed strategy, planning, outreach to pediatricians and other primary care physicians to encourage prompt recognition and early management prior referral to the CPAE clinic. The necessity of a full-time nurse to support the clinic was emphasized due to the large amount of clinical pre- and post-clinic work needed to make the clinic operate efficiently.

The clinic has already had a soft opening with the first patient seen in late November. This child was from Northwest Arkansas, had a preliminary diagnosis of CPAE and treatment initiated by the child's pediatrician, and the diagnosis was confirmed with longer-term treatment initiated in the clinic.

We are working toward a grand opening of the clinic in late February or early March at ACH pending scheduling.