HANDOUT 1

Guidelines for Accessing PANS/PANDAS Treatment in Arkansas

To make treatment for children with Postinfectious Autoimmune Encephalopathy (PANS/PANDAS) more accessible in Arkansas:

- The Arkansas Children's Hospital Childhood Post-infectious Autoimmune Encephalopathy (CPAE) Center of Excellence, should provide information on the medical standard-of care guidelines for diagnosing and treating Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Acute-onset Neuropsychiatric Disorders Associated with Streptococcus (PANDAS).
 - A. The information should incorporate the guidance provided by the NIH/NIMH in conjunction with the The PANS/PANDAS Research Consortium https://www.pandasppn.org/guidelines/ along with other medical references such as https://www.pandasppn.org/ research-library/
 - B. The guidelines should also include summary sheets and flowcharts describing PANS/PANDAS diagnosis and treatment (e.g. https://www.pandasppn.org/pans/)
 - C. By way of example, the guidelines might stipulate that:
 - A licensed physician (e.g. Pediatrician, Psychiatrist, Developmental Pediatrician, etc.), after having treated with two or more lessintensive therapies (e.g. limited course of nonsteroidal antiinflammatory drugs (NSAIDs), corticosteroids, selective serotonin reuptake inhibitors (SSRIs), behavioral therapy, short-course antibiotic therapy) have been tried and were not effective, AND
 - A consultation and recommendation is issued by a pediatric subspecialist (e.g., pediatric neurologist, neurologist, immunologist, rheumatologist, infectious disease) for IVIG treatment, THEN
 - Up to 3 monthly immunomodulatory courses of intravenous immunoglobulin (IVIG) therapy is recommended for treatment of PANDAS and PANS, ADDITIONALLY
 - A reevaluation at 3 months by the pediatric sub-specialist is required for continued therapy of IVIG. This evaluation must