



Children's Postinfectious Autoimmune Encephalopathy Center

Autumn 2022 Newsletter

[The Children's Postinfectious Autoimmune Encephalopathy \(CPAE\) Center of Excellence at the University of Arizona Steele Children's Research Center](#) provides clinical care, education, and utilizes research to better understand autoimmune encephalopathy.

With your participation in our research registry and biospecimen research studies, you are contributing to this increased understanding.

We are pleased to share this "inside look" at the work of the CPAE Center and the progress that is being made. Your continuing support for and involvement in the Center is greatly appreciated -- thank you!

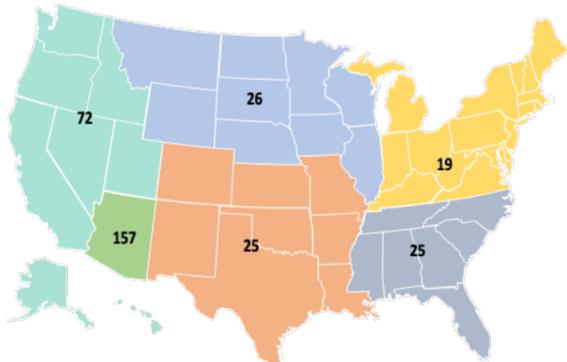
WHY A REGISTRY?

The physician-researchers associated with the **University of Arizona's Children's Postinfectious Autoimmune Encephalopathy (CPAE) Center of Excellence** began seeing and treating children with **PANS** (*Pediatric Acute-Onset Neuropsychiatric Syndrome*) and **PANDAS** (*Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections*) in 2016. In the years since then, our multidisciplinary team has worked with many hundreds of families, not just from Arizona but from across the country and around the world.

If your child was seen at the Banner/University of Arizona CPAE Clinic in Tucson, you likely were invited and encouraged to enroll your child in the **CPAE Patient Registry**. To those who opted in, we want to say, "Thanks!" and explain more about why that participation is so important.

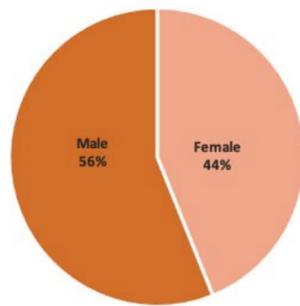
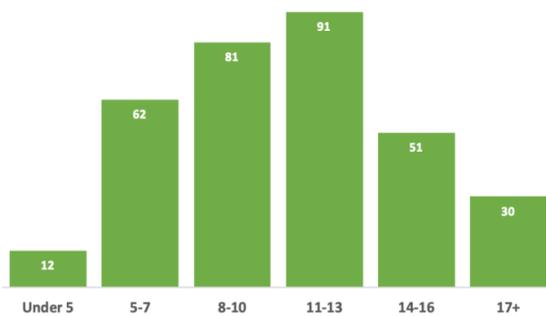
Patient registries are a means of collecting vital information to increase medical understanding of relatively rare and/or under-studied diseases. Data about symptoms, diagnosis, disease course, treatments and demographics on each patient is combined with many others to provide fertile ground for scientific study. The patient or parent must "opt-in" to be included in the registry, and personal data is guarded by rigorous confidentiality protections.

To date, the Arizona CPAE Patient Registry has been able to gather information on 327 children served by our clinic. The graphics here illustrate some of the characteristics of these children. While the majority of the children in our registry are from Arizona families, we are also seeing significant numbers from other parts of the United States and beyond.

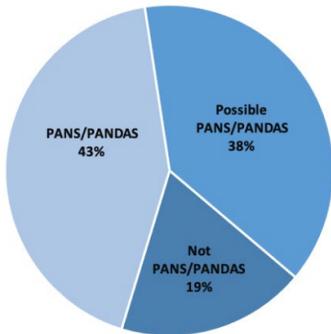


"When a concerned parent first contacts us, we do a lot on information-gathering right at the start," says Jessica Jones West, CPAE Clinic Nurse Navigator. "We want to make sure that our services are appropriate for their child's needs, especially if the family is travelling from far away. Those who meet the screening criteria are then scheduled for an appointment and invited to participate in the patient registry."

The cases in our registry include both boys and girls, currently reflecting a somewhat higher percentage of males. The graph below shows the ages at which children joined the registry, which is typically the date when they were first seen clinically.



Every child seen at the CPAE clinic has serious medical concerns, but not all are found to have PANS or PANDAS. Some cases clearly meet the diagnostic criteria upon first examination; others have symptoms and clinical histories that require more thorough investigation. Following the initial consultation, each family receives an initial diagnosis based on preliminary findings. Among the registry participants, the distribution of initial diagnoses were as shown below.



"Each child that comes to our clinic has some PANS/PANDAS symptoms, but not every child meets the full diagnostic criteria," says Dr. Michael Daines, Co-Director of the CPAE Center of Excellence. "There are other serious life-threatening conditions with similar appearances and symptoms, such as tics, autism, obsessive-compulsive disorder, thyroid disease, celiac disease, and other encephalopathies. We look carefully at each situation to ensure that a child receives the correct diagnosis and is directed toward the most appropriate course of treatment."

Data is continuously collected from the families that choose to participate in the registry, both through self-report surveys and clinical follow-ups. As the registry grows, the extracted data will provide a clearer picture of PANS and PANDAS, leading to better diagnosis and treatment outcomes. "We are learning a great deal about where our further research should be focused," says CPAE Center of Excellence Co-Director Dr. Sydney Rice. "Looking at data from the children in the registry is immensely valuable for the development of better diagnostic tools and more effective treatments that will benefit children far into the future."

For more information or to participate in the CPAE Patient Registry, contact Linnette Mayate, Program Coordinator, at peds-cpae@email.arizona.edu

