Every child seen at the CPAE clinic has serious medical concerns, but not all are found to have PANS or PANDAS. Some come 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.

The CPAE Patient 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 Loretta Mayap, Program Coordinator, at peds-cpae@email.arizona.edu.