Curriculum Vitae for Tara Richardson, M.D.

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EDUCATION

07/2013 – 11/2017	University of Kansas School of Medicine, Wichita, KS Psychiatry Residency
07/2009 – 05/2013	University of Kansas School of Medicine, Wichita, KS Doctor of Medicine
06/2008 – 06/2009	University of Kansas School of Medicine, Kansas City, KS Post Baccalaureate Program
08/2004 – 05/2008	University of Kansas, Lawrence, KS Bachelor of Arts in Anthropology

LICENSURES AND CERTIFICATIONS

2019 – Present	Missouri Board of Healing Arts License #2019025536
2019 – Present	Medical Board of California Medical License #A 162163
2018 – Present	American Board of Psychiatry and Neurology Board Certification
2015 – Present	Kansas State Board of Healing Arts Medical License #0438478

PROFESSIONAL EXPERIENCE

06//2019 – Present	Independent Contractor currently working with the following practices and locations: Integrated Psychiatric Consultants, P.A. FreeState Healthcare in Wichita, KS and several associated rural clinics KVC Children's Psychiatric Hospitals Mitchell Co. Hospital Geriatric Special Care Unit and Senior Life Enrichment Program South Central Kansas Medical Center Senior Health Unit in Ark City, KS Susan B. Allen Hospital in El Dorado, KS
12/2017 – 06/2019	University of Kansas School of Medicine – Wichita Department of Behavioral Health and Sciences Clinical Assistant Professor Medical Director of Generations Senior Behavioral Health Unit in Newton, KS Medical Director of Via Christi Psychiatry Residency Clinic in Wichita, KS

PUBLICATIONS

2019	Book chapter on SSRIs in Antidepressants: From Biogenic Amines to New Mechanisms of Action
2018	Journal of Gerontology and Geriatric Medicine: An Individualized Music-Based Intervention for Acute Neuropsychiatric Symptoms in Hospitalized Older Adults with Cognitive Impairment
2017	Expert Opinion on Drug Metabolism and Toxicology: Clinically Relevant Treatment Considerations Regarding Lithium Use in Bipolar Disorder

HONORS AND AWARDS

2019	Recognized IPC Provider Who Went Above and Beyond in 2019
2017	Chief Resident Award
2017	Award for Excellence in Research
2017	KU Psychiatry Departmental GEM (Going the Extra Mile) Award

2016	Resident Award for Excellence in Outpatient Care
2015	Most Outstanding Resident (as voted by medical students)
2013	Best Medical Student Performance in a Psychiatry Elective
2009 – 2013	Marshall and Mabel E. Flowers Scholarship Recipient
2004 – 2008	University of Kansas Watkins-Berger Scholar
2004 – 2008	University of Kansas Honors Program

PROFESSIONAL ORGANIZATIONS

2013 – Present	American Psychiatric Association
2013 – Present	Kansas Psychiatric Association, previously served as Councillor
2013 – Present	Medical Society of Sedgwick County
2013 – Present	Kansas Medical Society

PROFESSIONAL ACTIVITIES

2020 – Present	Integrative Psychiatry Institute Fellowship Program
2019 – Present	Volunteer Faculty at KU School of Medicine - Wichita
2018 – 2019	Resident Faculty Communication Committee
2018 – 2019	Expert Content Review for Kansas Journal of Medicine
2016 – 2017	Scholars in Medicine and Research Training Program
2016 – 2017	Chief Resident
2015 – 2016	Associate Chief Resident
2009 – 2013	Doctors' Notes (KU School of Medicine a capella group)

Testimony of Tara Richardson, M.D.
Prepared for the House Committee on Health and Human Services
December 14, 2020

PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome) is a medical disorder where a misdirected immune response results in both physical and psychiatric presentations. The diagnostic criteria for PANS are as follows:

1) Abrupt, acute onset of obsessive-compulsive disorder or severe restricted food intake
2) Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven categories:
    a) Anxiety, separation anxiety
    b) Emotional lability or depression
    c) Irritability, aggression, and/or oppositional behaviors
    d) Behavioral or developmental regression
    e) Deterioration of school skills (math skills, handwriting changes, ADHD-like behaviors)
    f) Sensory or motor abnormalities, tics
    g) Somatic signs: sleep disturbances, enuresis, or urinary frequency
3) Symptoms are not better explained by a known neurologic or medical disorder
4) Age requirement: None

The syndrome is made by clinical diagnosis, based on a child's medical history and physical examination. There are no specific lab tests or biomarkers that can be fully relied upon to make the diagnosis. PANS is a diagnosis of exclusion, meaning that patients should be fully worked up for other known illnesses or diseases that could be the cause of symptoms and these other conditions should be ruled out.

PANS can be caused by many triggers that create inflammation in the brain. These can include infections (such as upper respiratory infections, influenza, Mycoplasma, Lyme, and others) as well as metabolic disturbances and other environmental factors. PANDAS is the only known subset of PANS, specifically caused by Group A Streptococcal infections. PANDAS stands for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. While there are slight differences in the diagnostic criteria, for the purposes of this presentation PANDAS will often be encompassed by the term PANS.

Many studies are centered around PANDAS because we were following a phenomenon called Sydenham chorea. Sydenham chorea is a disruptive, writhing movement that is a well-established neurologic manifestation of rheumatic fever, a long-term sequelae of Group A Strep infection. As far back as the 1890s, personality and behavior changes were observed to be associated along with Sydenham chorea. A study in Brazil from 1998-2005 showed 100% of patients with multiple episodes of Sydenham chorea also had OCD, which predated the chorea by 2-4 weeks. This is still a relatively new diagnosis in terms of medical knowledge. The original researchers always believed PANDAS represents a small fraction of the number of patients with OCD and Tourette syndrome (who have tics). However, early on, when neurologists tested these patients for strep and it was not found, they questioned the existence of the condition. There was a national meeting held with proponents of both sides present, and this is where they

developed the term PANS (*1*). A group of experts known as the PANS Consortium issued diagnostic guidelines to help clarify the condition, and these diagnostic guidelines were published in the Journal of Child and Adolescent Psychopharmacology in 2017.

Further studies have led us to believe that the pathophysiology of PANS involves a similar mechanism to that of Sydenham chorea, where a genetically susceptible host contracts an infection such as strep. The body makes antibodies against the strep, but the bacteria puts antigens on its cell wall that look like human host. The human antibodies recognize these antigens, but cannot tell the bacteria from the human tissue. There is a misdirected immune response and begins attacking human tissue -- in the case of PANS, neurons in the part of the brain called the basal ganglia (*1*). The basal ganglia is the part of the brain involved in voluntary motor control, cognition and reward processes, executive functioning, behavior and emotions.The basal ganglia is also the site of most of the dopamine neurons in the brain and the target of most antipsychotic medications. PANS and PANDAS are encephalopathies, which means a disease that affects the functioning of the brain. Autoimmune encephalitis (AE) is a group of conditions that occurs when the body's immune system mistakenly attacks healthy brain cells, leading to brain inflammation. More research is needed to determine whether PANS is a form of AE but some children who are diagnosed with PANS are eventually diagnosed with AE. Treatment for the two conditions have many similarities.

The true prevalence of PANS is unknown due to poor diagnosis, but is estimated to affect 1 in 200 children each year. The average age of diagnosis is 3-13 years, though PANS has no age requirement. The peak age of onset is 4-9 years. An estimated 65% of PANS patients have a relapsing/remitting course, meaning that symptoms are improved or gone at times (remitting) and may return (relapsing). The initial triggers may vary from the secondary triggers (*2*). During each recurrence, symptoms can worsen, and new symptoms may manifest. While the diagnostic criteria describes an "acute onset," some children's initial symptoms are mild, are attributed to developmentally appropriate behavior, or are not diagnosed due to lack of education and awareness about the condition. Many children with PANS are diagnosed with a psychiatric illness and prescribed psychotropic medications rather than being evaluated and treated for an underlying infection. However, a timely diagnosis and appropriate treatment lead to better long-term outcomes.

Symptoms can range from mild to severe, and most children exhibit most of the symptoms. In mild cases, a child may continue to attend school In severe cases, symptoms can become life-threatening, often due to extreme food restriction or suicidality. The appropriate treatment involves a three-pronged approach, including antimicrobial treatment, immunomodulatory treatment, and symptomatic relief with psychotherapeutic treatments.

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In September 2019, my daughter Brielle was selected from her kindergarten class as a student who emulated their school motto - being responsible, respectful and resourceful. She adores everything about school and was excited to attend every morning. That being said, it was quite odd when she had a panic attack for the first time in her life on a Wednesday morning in October and ran inside from the bus stop, missing the bus and making her late for school. That evening, she began worrying that she may have accidentally swallowed a piece of eggshell in her scrambled eggs. Over the next 2 days, this progressed to concern that she may have accidentally swallowed a worm and then that she may have accidentally swallowed a significant amount of hair. She began checking her mouth for hair, and then began doing so incessantly.

Her anxiety began to become increasingly bizarre, but always ended in her certain death. For example, she saw a Starbucks commercial with a lightning sound and because she ate a cake pop from Starbucks months ago, this must mean that she was going to die. On the third day, she began to refuse all food due to fears of contamination. She walked back and forth between our living room and pantry for hours, crying because she was so hungry but she could not allow herself to eat. She began to have very repetitive speech, which at times regressed into that of a 2-year-old. She developed a motor tic, pursing and smacking her lips.

Over the course of 3 days, my healthy, neurotypical daughter developed the following:

- The most severe case of OCD I have ever seen as a psychiatrist
- Refusal to eat due to believing her food was contaminated and would kill her
- Severe separation anxiety to where she was unwilling to leave my side, day or night
- New-onset motor tic
- Severe mood swings and irritability
- Significant defiance, hyperactivity, impulsivity and difficulty concentrating
- Behavioral regression with “baby talk” and tantrums
- Sleep disturbance where she was awake through much of the night
- Abdominal pain, urgency and frequency during the day, bedwetting at night
- Hypersensitivity to touch, where she felt clothing was hurting her and would accuse us of hitting her after normal touch
- Episodes of a “terror-stricken look” with dilated pupils
- Aggression to the point of posturing to stab me with a pencil

Looking back, the only negative feedback we had received at her recent parent-teacher conference was that she had become very sloppy in her coloring (which we now know was a symptom as well). My daughter developed a textbook presentation of PANS. Out of 23 symptoms, she exhibited 19 to a moderate or severe degree.

One of the most concerning aspects of this for me, was my own lack of education in regards to PANS, despite having completed residency by that time. I had heard of PANDAS, but knew little more than that it was OCD symptoms that presented after a strep infection, believed that it was rare and that it ultimately did not change the course of treatment. During the course of her illness, I discussed her case with 7 other physician colleagues, and no one knew what to make of her symptoms. On the fifth day of symptoms, I called the on-call pediatrician, who was dismissive at best and suggested I follow up with outpatient neurology, which could take months. I took Brielle to the emergency room, and the ED physician diagnosed her with a UTI and discharged us without any answers or seemingly any significant concern. Out of desperation, I reached out to a colleague from medical school, who texted a pediatric neurologist on a Sunday morning, and they agreed to admit Brielle to the hospital for an encephalitis workup. Thankfully, the MRI and lumbar puncture were negative, but the strep test was negative as well and once again, there was no explanation for Brielle’s symptoms. Neither of them were aware of PANS. The medical team offered admission to the children’s psychiatric hospital -- however, I was the admitting psychiatrist on call. If this had been any other child in Wichita, she would have likely been transferred there. Ultimately we agreed to consult a pediatric clinical neuropsychologist, Dr. Kelli Netson, who was very familiar with PANS, and we had an official diagnosis after 7 days. As far as we know, Brielle’s PANS was triggered by a common virus, rhinovirus-enterovirus. As Dr. Netson has a PhD, I asked her where she referred these children for medical treatment, and she told me that she wasn’t aware of any providers in the area.

I was able to make contact with an expert immunologist out of the University of Arizona, who

was kind enough to provide me some guidance with the Stanford Treatment Guidelines, but since that point, I have been steering the ship as I am not aware of any other physicians in the area. The primary treatment has been ibuprofen, a course of oral steroids, significant dietary changes (primarily avoiding gluten, sugar and processed foods) and play therapy. We had seen a 90% reduction in symptoms by the time of our presentation to this committee in February of this year. I felt like I had my daughter back after 3 months. Even then, she was still refusing to eat through the entire school day as she believed the food was not safe for her, and the stay-at-home order in March was a blessing in disguise for us as we were able to focus on nutrition and minimizing stress. Now, a year after PANS came into our life, she is fully recovered at baseline, with mild OCD symptoms whenever her immune system is confronted with minor illness. My daughter's illness has absolutely been the most difficult thing that has ever happened in my life, but also one of the most humbling. I feel incredibly fortunate to be telling this story as we have a happy ending. I am now completing an additional year-long fellowship to be able to treat PANS more effectively, but only one of the 3 prongs of treatment is within my scope of practice as a psychiatrist.

As you listen to other testimonies, I hope ours highlights the importance of an early diagnosis and how this can ease the suffering of these children and the extreme burden on their families. I have seen a handful of other children with PANS since I first learned enough about the disorder to recognize its presentation. One child in particular struggled with extreme behavioral problems, frequent tics, aggression and suicidality. He had been suspended from school multiple times, and the police had been called to his home due to his behavior. His symptoms had been going on for 5 years by the time I saw him, and medications were of limited utility. Once we identified a diagnosis, we were able to discontinue his mood stabilizer and antipsychotic medications. He is doing well with diet and lifestyle changes. However, I do believe that cases like ours are the minority in Kansas. It is extremely difficult to find other physicians to help care for these patients, to even consider the diagnosis and provide an appropriate medical workup. Even as a psychiatrist myself, we had some form of contact with 12 physicians before we were able to obtain a diagnosis. I share this not to speak poorly of my colleagues as I hold myself responsible for my own lack of knowledge, but to demonstrate the dire need for widespread education about PANS. The medical education of our frontline providers has not caught up with the increasing prevalence of this condition. Most are not aware of the spectrum of symptoms, the differences between the acute and chronic illness, and the treatment guidelines that exist. Most families do not have the ability to contact 12 physicians in a matter of days, nor should they need to. A child should not need a physician as a parent to continue to push for appropriate evaluation and treatment. Lastly, the ability of a child to receive life-saving treatment should not be dependent on their parents' income, and I believe you will learn more about these inequities with our next several speakers.

Respectfully,

Tara Richardson, M.D.

Works Cited

1. Swedo, Susan. "A Historical Perspective on PANS". Royal University Hospital in Saskatoon, Canada. 10 October 2015.

2. Zagor, F., & Kapetanakis, C. (2020, June 20). PANDAS/PANS - The Frequently Misdiagnosed Behavioral/Neurological Syndrome. Retrieved December 10, 2020, from aspire.care/clinicians/natcon-behavioral-health-presentation/

The majority of the graphics used for the oral presentation are courtesy of ASPIRE (The Alliance to Solve PANS & Immune-Related Encephalopathies, www.aspire.care) and/or Susan, Swedo, M.D.