

AIR-P LEND Seminar Series: Neurology

Purpose: This document corresponds with the Neurology video in the AIR-P LEND Seminar Series. It outlines the video’s content and provides suggestions on how to use this resource.

Research Node: Neurology

Summary: In this video, the AIR-P Neurology Research Node leaders will discuss topics related to neurology and autism, including: (1) the “big” topic areas this node covers (2) gaps in the field (3) and a more in-depth discussion of the intersection between epilepsy and Autism.

Learning objectives:

- Understand what a seizure and epilepsy is.
- Understand how epilepsy intersects with autism.
- Brief overview of transition to adulthood in autism.

Outline:

Section of Video	Content Outline & Talking Points	Presenter(s)	Time allotted*
General Overview	<ol style="list-style-type: none"> 1. Welcome 2. Context <ol style="list-style-type: none"> a. Give context on AIR-P. <ol style="list-style-type: none"> i. Autism Intervention Research Network on Physical Health AIR-P Network (ucla.edu) ii. AUCD - Autism Intervention Research Network on Physical Health (AIR-P) iii. Network of researchers b. Describe the video’s topic. 3. Overview of Node <ol style="list-style-type: none"> a. Topic 1: Co-Occurring Neurologic conditions are prevalent in autistic individuals b. Topic 2: Goals of the Neurology Research Node <ol style="list-style-type: none"> i. Improve identification, awareness, and treatment of common co-occurring neurologic conditions in autistic individuals across a lifespan. (e.g., motor challenges are highly prevalent and often under recognized and under screened). 	<p><u>Presenter (Node Leader):</u> Rujuta B. Wilson, MD, AIR-P Assistant Professor in Pediatric Neurology and Psychiatry David Geffen School of Medicine at UCLA; Associate Program Director Pediatric Neurology</p>	5 min

	<ul style="list-style-type: none"> ii. To develop and test the neurologic, physical health and wellbeing, and developmental outcomes of a motor-based intervention for autistic individuals iii. Disseminate information on co-occurring Neurologic conditions in autism to the community and health care providers. c. Topic 3: Other Specific Research Priorities of the Node <ul style="list-style-type: none"> i. Understanding the developmental Trajectories and Adult Outcomes ii. Coordinating Neurological Care 4. Learning objectives <ul style="list-style-type: none"> a. Understand what a seizure and epilepsy is. b. Understand how epilepsy intersects with Autism 		
Overview of Epilepsy and transition.	<ul style="list-style-type: none"> 1. Talking Points <ul style="list-style-type: none"> a. Basic Definitions <ul style="list-style-type: none"> i. What are Seizures? ii. What is Epilepsy? b. Epilepsy in Autism <ul style="list-style-type: none"> i. Prevalence of Epilepsy in Autism ii. Pathophysiology of Epilepsy in Autism c. Work up and treatment of Epilepsy in Autism <ul style="list-style-type: none"> i. Pediatric Treatment ii. Transitioning to Adult Care 	<p><u>Presenter (Node leader):</u> Rujuta B. Wilson, MD, AIR-P Assistant Professor in Pediatric Neurology and Psychiatry David Geffen School of Medicine at UCLA; AIR-P Neurology Node Director. UC-LEND Faculty.</p> <p>Gary Stobbe, MD, University of Washington AIR-P CRE Lead</p>	5-10 min
Panel Discussion	<ul style="list-style-type: none"> 1. Introductions <ul style="list-style-type: none"> a. CRE leads/co-leads and panel discussants introduce AND describe themselves (see example above). 2. Structure/Facilitator notes <ul style="list-style-type: none"> a. Topic 1: Parent vs personal vs provider perspectives on accessing Epilepsy care and diagnosis for Autistic individuals. b. Topic 2: Parent vs personal vs provider perspectives on how to tell a non-seizure from a seizure in autistic individuals <ul style="list-style-type: none"> i. Consider both nonverbal and verbal autistic individuals c. Topic 3: How can we improve access to care for pediatrics? For transitioning to adult care? To adults? 	<p><u>Facilitator (CRE lead/co-leads):</u> Gary Stobbe, MD, University of Washington AIR-P CRE Lead</p> <p>Andrea Deisher MPH, RN, BSN, Project Director of CYSHCN and VaxFactsDDNY Projects, Albert Einstein College of Medicine AIR-P CRE</p> <p><u>Panel (self-advocate/lived experience, caregiver experience, professional experience/node leader):</u> Rujuta B. Wilson, MD, AIR-P</p>	25-35 min

	<ul style="list-style-type: none"> i. Concerns about getting an EEG (difficulty with having head touched or being restrained) ii. Medical Trauma/Fear iii. Lack of transition resources <p>3. Closing summary</p>	<p>Assistant Professor in Pediatric Neurology and Psychiatry David Geffen School of Medicine at UCLA; Associate Program Director Pediatric Neurology</p> <p>Zachary J. Williams M.D./Ph.D Candidate (Year 5), Vanderbilt University, AARB</p> <p>Nancy Hall-Burke Caregiver/Parent Experience</p>	
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Tips to Use this Resource:

- “Suggestion for parents to produce "social stories" to explain step-by-step medical procedures to help the child understand what will be happening to them during ANY type of medical procedure. Rather than using "generic" images, I like us use actual photos”
- “Suggestion for parents, that have extreme difficulty obtaining blood draws for their kiddos, they may be interested into looking into a "mobile" phlebotomist. The procedure is done in your home, where your child feels more comfortable, less overwhelming, and in a calm environment.”
- “On-going concerns that many parents of autistic children, specifically those that have lower-functioning autism, have are transitioning to adulthood; ability to live independently; ability to have a job (with a job coach); and finding and securing long-term housing with 24/7 caregivers.”

Sample discussion questions:

1. What are some reasons that an autistic individual and/or their family may or may not struggle to get care for co-occurring neurological conditions including epilepsy?
 - a. Think about concerns and questions from families:
 - i. Obtaining referrals
 - ii. Is the neurologist accepting new patients?
 - iii. Is this a life-long disorder?
 - iv. What are the expenses for office visits, testing and medications?
 - v. What expenses will insurance cover?
2. What are some questions that an autistic individual and/or their family may want to consider asking their provider prior to pursuing treatment/diagnosis/care for potentially co-occurring neurological conditions including epilepsy?
 - a. Think about concerns and questions from families:
 - i. The EEG procedure may be challenging for patient, especially when the electrodes are being placed on the head; being "tethered" to the equipment for

- up to 48 hours; and keeping the electrodes in place (child may try to pull them off).
- ii. Will they have to have more than one anti-seizure medication?
 - iii. What are the long-term effects from the medications? Could they cause organ damage?
 - iv. Will the medication(s) cause aggression, sleep interruption; affect appetite?
 - v. How often will my child need blood draws to monitor levels? It may be extremely difficult to obtain blood draws. These procedures can be extremely traumatic for patient.
3. Should screening for Epilepsy and other co-occurring neurological conditions be considered the standard of care for any autistic individual?

Contextual Articles:

- Liu, X., Sun, X., Sun, C., Zou, M., Chen, Y., Huang, J., ... & Chen, W. X. (2022). Prevalence of epilepsy in autism spectrum disorders: A systematic review and meta-analysis. *Autism*, 26(1), 33-50. <https://doi.org/10.1177/13623613211045029>
- Paul T. Shattuck, Lynette Lau, Kristy A. Anderson, Alice A. Kuo; A National Research Agenda for the Transition of Youth With Autism. *Pediatrics* April 2018; 141 (Supplement_4): S355–S361. 10.1542/peds.2016-4300M <https://doi.org/10.1542/peds.2016-4300M>
- Bolton PF, Carcani-Rathwell I, Hutton J, Goode S, Howlin P, Rutter M. Epilepsy in autism: features and correlates. *Br J Psychiatry*. 2011 Apr;198(4):289-94. doi: 10.1192/bjp.bp.109.076877. PMID: 21972278; PMCID: PMC3065774. DOI: [10.1192/bjp.bp.109.076877](https://doi.org/10.1192/bjp.bp.109.076877)
- Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.
- Christelle M. El Achkar, Sarah J. Spence; Clinical characteristics of children and young adults with co-occurring autism spectrum disorder and epilepsy. *Epilepsy and Behavior* January 2015; Vol. 47. <http://dx.doi.org/10.1016/j.yebeh.2014.12.022>