



Autism Intervention Research
Network on Physical Health

AIR-P LEND Seminar Series

GENETICS RESEARCH NODE



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Learning Objectives

- 1) Understand why genetic testing for autistic individuals and their families is important.
- 2) Understand the importance of taking a lifespan approach when considering genetic testing for autistic individuals.
- 3) Understand important ethical considerations related to genetic testing for autistic individuals.





Genetics Research Node: General Overview



Topic 1: Diagnostic journey barriers to genetic testing access (costs, knowledge about options, etc.).



Topic 2: Types of genetic testing and their clinical utility in medical practice.



Topic 3: General population literacy awareness about genetic risk and clinical knowledge and genetic counseling gap for medical providers (e.g., informed consent, interpretation, risks and limitations of genetic testing).



Topic 4: Broad implementation and ethical implications of genetic testing (vulnerable populations, stigmatization, privacy and confidentiality, family issues, obligation to disclose, premature marketing, reliable interpretation).



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Genetics Research Node: Gaps in the Research



Topic 1: What proportion of autistic people find answers from genetic tests? Which specific demographic or clinical factors (e.g., sex, age of diagnosis, "simplex" vs. "multiplex" autism, ID status, dysmorphology, co-occurring conditions, etc.) best predict a high likelihood of a positive genetic result?



Topic 2: What is the clinical utility, measurable benefit, and impact of positive genetic tests on clinical care (psychological, plan and cost of care, early diagnosis, prognosis)? Based on these benefits, how "cost-effective" are these tests when applied at a population level?



Topic 3: What interventions can improve family history self-knowledge, natural history and phenotypic spectrum of rare conditions that present with neurodevelopmental differences, and access to underserved populations?



Topic 4: Can practice guidelines be developed that ensure ethical research and clinical use and implementation of genetic data analysis?



Genetics Research Node: Panel Discussion



Topic 1: Parent vs provider vs personal perspectives on genetic testing.



Topic 2: Should every family with an autistic child (or adult) be offered genetic testing?



Topic 3: What are the ethical concerns associated with genetic data and what can be done to address them?



Topic 4: How can we improve access to genetic testing?

Connect with folks from this seminar!

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Website

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The structure, instructions, and accessibility guidelines of this AIR-P LEND Seminar Series were developed in part based on existing processes and content used to develop the PacWest ITAC LEND Learning Modules.