

Learning Activities: Joubert Syndrome and Related Disorders

In-Class Activity: Systems Mapping Activity

Each group creates a visual map of the systems the author interacted with (e.g., medical, educational, therapeutic). Include:

- Points of access
- Barriers encountered
- Supportive individuals or institutions
- Gaps in coordination or communication

In-Class Activity:

In small groups, *considering the case report by Alam et al. (2021) on Joubert syndrome, discuss how interdisciplinary teaming can be applied to support infants and toddlers with rare neurodevelopmental disorders. What unique challenges arise when coordinating care for children with complex medical and developmental needs, and how can early intervention teams ensure culturally responsive, evidence-based support for families?*

In your response, consider:

- The role of physical therapy and other disciplines in managing motor and developmental delays in Joubert syndrome.
- How teaming practices can address diagnostic uncertainty and evolving needs.
- Strategies for integrating family voice and priorities into service planning.
- The importance of communication, role clarity, and shared goals in transdisciplinary care.

In-Class Activity: Based on the video ([Joubert Case Study](#)):

Break into small groups and discuss:

- What were the most striking features of the child's presentation?
- How did the family describe their journey through diagnosis and care?

What interdisciplinary supports were evident or missing?