HTP – LAN: The Human Trisome Project - Latin America Network. Second Year of Activities.

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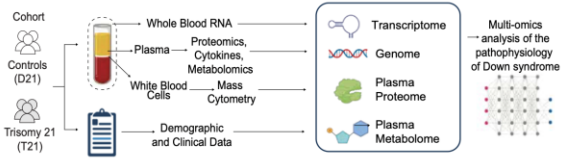
BACKGROUND

In September 2023, we launched the Human Trisome Project – Latin America Network (HTP–LAN) as an extension of the ongoing Human Trisome Project (HTP, NCT02864108), a longitudinal observational study focused on trisomy 21. HTP – LAN includes research sites in Mexico, Colombia, Brazil, Argentina, and Chile. Our aim is to capture the diversity of the Latino community and the variable presentation of DS in this population.

Year 1 activities. September 2023 - 2024

September 2023.
Weekly virtual meetings to discuss research activities and coordinate data collection and analysis. Local protocols developed and approved for a "Pilot Project," to prove feasibility for the long-term project.

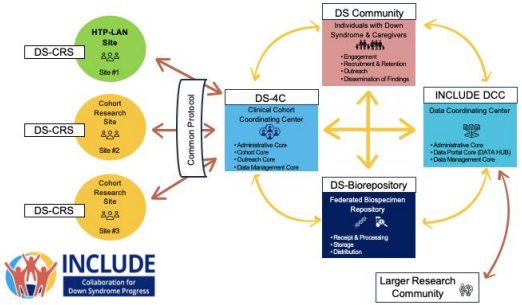


November 2023.
- In-person workshop in Denver
- Protocol harmonization and data management planning

December 2023.
HTP-LAN submits proposal in response to RFA-OD-24-003: *Down Syndrome Cohort Research Sites (DS-CRS) for the Down Syndrome Cohort Study Program (DS-CDP) across the lifespan for the INCLUDE Project*.

April, June and July 2024.
Team members attend NIH-INCLUDE Investigators Meeting in Washington, D.C., T21RS conference in Rome, Italy, and NDSC annual convention and DSMIG symposium at Phoenix, Arizona, presenting study activity progress. [1,2]

Year 2 activities. September 2024 – to date



September 2024. HTP-LAN received the Notice of Award from NICHD (U01HD1164469) to become a component of the DS-CDP.

February 2025. HTP- LAN attends virtual INCLUDE DS-CDP Network Annual Meeting and NIH Clinical Data Management Workshops. We travel to Colorado to participate in neurocognitive assessment training at Colorado State University, led by Dr. Deborah Fidler and her team.

April-May 2025. Feasibility study of biospecimen collection starts. First participant was enrolled in Chile. By the end of May 2025, more than 45 participants have enrolled in the study. The first shipment of biospecimens successfully arrived in Denver, Colorado for processing and characterization in June 2025. We have also prepared a manuscript detailing the lessons learned from international biobank coordination efforts.

CONCLUSIONS

HTP - LAN activities will enrich local research cohorts as well as the DS-CDP Cohort with racial, ethnic, and socio-cultural diversity necessary for investigations considering individuals with DS.

FUTURE WORK

Ongoing cross-training and feasibility efforts will ensure the successful launch of the international component of the DS-CDP, which in turn will fuel discoveries about the mechanisms modulating the variable developmental and clinical presentation of DS..

REFERENCES

1. Espinosa JM, Fidler DJ, Chelales EM, et.al. The Human Trisome Project - Latin America Network. [Poster]. Rome, Italy: Trisomy 21 Research Society; 2024 June.
2. Espinosa JM, Fidler DJ, Eguiarte-Diaz G, et.al. The Human Trisome Project - Latin America Network. [Poster]. Phoenix, Arizona: Down Syndrome Medical Interest Group-USA annual symposium; 2024 July.