

Prenatal Preparation: Actions and Results (PREPARE): Longitudinal interviews with parents whose child was diagnosed with a genetic condition

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METHODS

- ❖ Three participating clinical sites; University Hospitals Cleveland Medical Center, Ohio; University of North Carolina, Chapel Hill, NC; and Mt. Sinai Health System, New York
- ❖ Parents participated in either 3 (prenatal cohort) or 2 (postnatal cohort) semi-structured telephone interviews.
- ❖ Participants received a \$25 gift card after each interview.
- ❖ Interviews conducted between December 2020 and May 2023 were audio recorded, transcribed, and de-identified.
- ❖ Interviews explored parental experiences of pre- and postnatal screening, diagnostic testing, and results delivery; investigated the social and informational support received by families from initial testing through one-year post-birth; and asked what preparation meant to them throughout this period.
- ❖ Codebook was iteratively developed using principles derived from grounded theory; transcripts were coded and analyzed using the Dedoose qualitative analysis software package. 20% of transcripts were double-coded, with differences resolved by analytic consensus.
- ❖ Approved by the Institutional Review Board of University Hospitals of Cleveland Medical Center.

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Please refer to the PREPARE website and blog post for more information →
<https://prepare-study.net/2023/05/24/the-prepare-study-at-ispd-2023/>