A novel visualization of state-by-state variability in newborn screening (NBS) highlights underrepresentation of lysosomal storage disorders

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Introduction
- NBS is a program run by each state that detects a variety of treatable infantile-onset metabolic and genetic disorders
- The conditions screened for on NBS vary state-by-state, though the extent of variation has not previously been assessed visually.
- The RUSP is a list of 35 minimum recommended screening tests for states to include on NBS
- Most LSDs listed have enzyme replacement therapies treatments available; other disorders are treated with diet, nutrient supplementation, & by avoiding fasting.

Methods
Data on newborns screening offerings by state was manually downloaded from newsteps.org in December 2021. State-level data was downloaded from Wikipedia using the rest API (version 0.3.6) in December 2021. Visualization created using the R programming language (version 4.0.3).
- https://www.newsteps.org/resources/data/visualizations/newborn-screening-status-all-states

Conclusions
- Providers that serve patients from multiple states should be aware of the variability that exists in NBS
- Could be used to help advocate for expanding NBS options, particular between neighboring states in regions (e.g. the South) with wide discrepancies in NBS offerings

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Population per state
Total number of conditions tested per state.
Background color refers to the region of the US

There are 32 conditions screened for in all 50 states

Tennessee, one of 3 states offering the most comprehensive NBS, screens for twice as many conditions as Arkansas, a geographic neighbor.

In general, states in the Northeast offer more NBS options. Most have adopted RUSP guidelines for LSDs.

States in the South have the greatest variability in NBS offerings, including LSDs.

There’s no clear relationship between the political leaning of each state and LSD screening.

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