

Senate Health & Human Services

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SB22-186 Create Colorado Rare Disease Advisory Council

Typed Text of Testimony Submitted

Name, Position, Representing	Typed Text of Testimony
Gregory Bonn For Self	<p data-bbox="565 373 844 483">Gregory Bonn 1492 W. Long Avenue Littleton, CO 80120</p> <p data-bbox="565 525 1412 703">Dear Committee, I would like to offer my support for SB22 -186, Create Colorado Rare Disease Advisory Council. The proposed Rare Disease Advisory Council’s mandate would provide a united voice to the disparate individuals affected by rare diseases.</p> <p data-bbox="565 714 1453 966">A key component of making this advisory council effective is ensuring that it works with the current newborn screening programs located in the Colorado Department of Public Health (CDPHE). The newborn screening programs are the key links to the rare disease community and CDPHE. Increasing stakeholder engagement with the programs is beneficial for moving the programs forward. The advisory council can provide a strong connection to the rare disease community.</p> <p data-bbox="565 976 1453 1312">Current stakeholder engagement with the newborn screening programs is sporadic. Concerns from stakeholders about interpretation and implementation of stakeholder-initiated legislation is ongoing. Fiscal management of fees dedicated to these programs is a regular issue. This advisory council could act by “Evaluating and making recommendations concerning newborn screening programs”. This would provide stakeholders a consistent group of non-CDPHE experts acting on their behalf to ensure these programs are leading Colorado Newborn Screening in an equitable manner.</p> <p data-bbox="565 1312 876 1344">Thank you for your time.</p> <p data-bbox="565 1354 690 1386">Sincerely,</p> <p data-bbox="565 1428 747 1459">Gregory Bonn</p>