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ACLU POSITION: NEUTRAL

**TESTIMONY ON 25-H 5023,
RELATING TO HEALTH AND SAFETY -- RARE DISEASE ADVISORY COUNCIL
February 6, 2025**

The ACLU of Rhode Island has no position generally on this bill that would create a rare disease advisory council. However, we did wish to express our organization's support for one particular provision relating to the Council's public meetings.

Specifically, the legislation would require the council to "provide opportunities for the public to hear updates and provide input into their work." As committee members are aware, the state's Open Meetings Act requires meetings of public bodies to be open to public view, but it does not provide a right to public *participation*. In a report that we issued last year on the public comment policies of municipal public bodies, we emphasized the importance of offering the public an opportunity to speak at meetings.¹

The same rationale applies to extending this opportunity to meetings of state public bodies, so we appreciate that this bill makes explicit that people will have the chance to interact with the council in a meaningful way. We hope this will serve as a model, and that similar language will regularly be included in laws creating new public bodies like this one at the state level.

¹ "Voicing Concerns: Public Comment Policies of Rhode Island City and Town Councils and School Committees," February 2024, <https://www.riaclu.org/en/publications/report-voicing-concerns-public-comment-policies-rhode-island-city-and-town-councils-and>