



MISSOURI HOUSE OF REPRESENTATIVES
WITNESS APPEARANCE FORM

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|--|---------------------------------|---------------------------|---|
| BILL NUMBER: HB 2740 | | DATE: 1/20/2026 | |
| COMMITTEE: Higher Education and Workforce Development | | | |
| TESTIFYING: <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES | | | |
| WITNESS NAME | | | |
| INDIVIDUAL: | | | |
| WITNESS NAME: ARNIE C. AC "HONEST-ABE" DIENOFF-STATE PUBLIC ADVO | | PHONE NUMBER: | |
| BUSINESS/ORGANIZATION NAME: | | TITLE: | |
| ADDRESS: | | | |
| CITY: | | STATE: | ZIP: |
| EMAIL: | ATTENDANCE: In-Person | | SUBMIT DATE: 1/20/2026 11:41 PM |

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

I hope that this new Governing Board will not sit idle and actually get true and cutting-edge Research Accomplishments.



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| WITNESS NAME | | |
| INDIVIDUAL: | | |
| WITNESS NAME: JOHN RUTH | | PHONE NUMBER: |
| BUSINESS/ORGANIZATION NAME: | | TITLE: |
| ADDRESS: | | |
| CITY: | | STATE: ZIP: |
| EMAIL: | ATTENDANCE: | SUBMIT DATE: 1/20/2026 12:00 AM |
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| WITNESS NAME | | | |
| BUSINESS/ORGANIZATION: | | | |
| WITNESS NAME: RICHARD BAROHN | | PHONE NUMBER: 573-268-8397 | |
| BUSINESS/ORGANIZATION NAME: UNIVERSITY OF MISSOURI SCHOOL OF MEDICINE | | TITLE: | |
| ADDRESS: ONE HOSPITAL DRIVE | | | |
| CITY: COLUMBIA | | STATE: MO | ZIP: |
| EMAIL: | ATTENDANCE: | SUBMIT DATE: 1/20/2026 12:00 AM | |
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| WITNESS NAME | | |
| INDIVIDUAL: | | |
| WITNESS NAME: SARAH BERRY | | PHONE NUMBER: |
| BUSINESS/ORGANIZATION NAME: | | TITLE: |
| ADDRESS: | | |
| CITY: | STATE: | ZIP: |
| EMAIL: | ATTENDANCE: Written | SUBMIT DATE: 1/17/2026 12:44 PM |

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I submit this testimony in opposition to HB 2740, not in disregard for the importance of rare pediatric disease research, but out of concern for how this bill structures governance, influence, and accountability within publicly funded scientific institutions.

Research involving children with rare and life-threatening conditions demands the highest ethical standards, including strong protections for academic independence, transparency, and freedom from undue political or commercial influence. HB 2740 establishes a governance board that includes legislative appointees and industry or nonprofit representatives, yet it does not clearly define the limits of that board’s authority. The absence of explicit boundaries between advisory oversight and decision-making power creates a risk that research priorities, funding direction, or reporting could be influenced by interests outside of scientific merit and patient welfare.

The bill also lacks robust conflict-of-interest safeguards. While collaboration with nonprofit or industry partners can be valuable, governance structures must include clear disclosure, recusal, and ethics requirements—especially when vulnerable pediatric populations and emerging medical technologies are involved. HB 2740 does not provide those protections in statute.

Additionally, the bill provides only a single patient or family advocate seat on the governance board. Given the diversity and complexity of rare pediatric diseases, this level of representation is insufficient to ensure that affected families meaningfully shape oversight decisions that may directly impact them. While HB 2740 requires an annual public report, reporting alone does not substitute for structural safeguards. Transparency after the fact does not prevent influence before decisions are made.

Children facing rare and devastating illnesses deserve research guided by science, ethics, and patient need—not by political appointment or commercial proximity. Until this bill clearly limits governance authority, strengthens conflict-of-interest protections, and expands meaningful patient representation, it does not meet the standard of care owed to the public or to the families it purports to serve.

For these reasons, I respectfully oppose HB 2740.