

HCS HB 2740 -- PEDIATRIC DISEASE TASK FORCE

SPONSOR: Steinmeyer

COMMITTEE ACTION: Voted "Do Pass with HCS" by the Standing Committee on Higher Education and Workforce Development by a vote of 9 to 0 with 1 member voting present. Voted "Do Pass" by the Standing Committee on Rules-Administrative by a vote of 11 to 0.

The following is a summary of the House Committee Substitute for HB 2740.

This bill establishes a task force within the Department of Higher Education and Workforce development composed of 14 members as specified in the bill, which includes two members from the House of Representatives appointed by the Speaker of House and two members of the Senate appointed by the President Pro Tem of the Senate. The Governor will appoint eight additional members as outlined in the bill.

The task force is required to meet at least quarterly beginning January 1, 2027 and submit an annual report by December 31st to the General Assembly detailing the following:

- (1) Research initiatives focused on genetic or pediatric diseases;
- (2) Key outcomes achieved;
- (3) Funds expended and leveraged; and
- (4) Any legislative recommendations.

This provision expires on December 31, 2030.

The following is a summary of the public testimony from the committee hearing. The testimony was based on the introduced version of the bill.

PROPONENTS: Supporters say that there are many Missouri children fighting rare pediatric diseases and having some accountability and transparency on what public resources are being used for to help combat these diseases is important. This bill will have focused transparency on outcome driven efforts that is patient and family centered and addresses real world impacts on families. Having a formal governance structure will advance research into key areas specifically the rare pediatric and neurogenetic that

can be treated with radioisotopes. Diseases that are rare sit in the shadows and having a the opportunity to include a parent perspective is important.

Testifying in person for the bill were Representative Steinmeyer; Richard Barohn, University of Missouri School of Medicine; John Ruth; and Arnie C.Dienoff.

OPPONENTS: There was no opposition voiced to the committee.

Written testimony has been submitted for this bill. The full written testimony and witnesses testifying online can be found under Testimony on the bill page on the House website.