

June 3, 2020

TO: Senate Health, Human Services and Medicaid Committee

FROM: Pat McKnight, MS, RDN, LD  
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Chairman Burke and Members of the Committee, I am adding my support for HB 412 – Rare Disease Advisory Council.

I have a grandniece, Lysie Barchanowicz, who has Rett Syndrome. This is one of those rare diseases. I have seen Lysie's mother, my niece Karen, struggle for many years to make the necessary arrangements for her daughter's care. Karen has good family support which has made things a little easier for her. Not all families have this support. The research on treatment has been promising – too late for Lysie, but may help others.

Families with these children need research and public awareness so that progress towards prevention, treatment and cure will move forward for these diseases.

Please support HB 412