* Good morning.  I wish to thank Chairman Barrett and the committee for allowing me to speak today.  My name is Pat Clements.  I am a pediatrician who takes care of newborn babies in the hospital.  I speak in support of this bill on behalf of the Indiana Chapter of the American Academy of Pediatrics   (?others)
* This bill creates a pathway through which new conditions can be approved for inclusion on the newborn screen.  The newborn screen is a blood test that babies get after birth that tests for dozens of rare, but treatable, serious medical conditions.  As doctors, it is important to know about these conditions quickly.  As medical advances occur, there will be opportunities to add new conditions to the newborn screen.
* This bill would create an advisory council that would bring together a multidisciplinary team from across our state, including experts in genetics, metabolism, hematology, and neonatology.  It would also bring together family advocates and experts in public health, laboratory medicine, and medical ethics.
* This new process will allow a clear and defined pathway that families, patient advocate groups, and healthcare providers can use to nominate a condition to be added to the newborn screen.
* As a pediatrician that takes care of newborn babies, I have seen firsthand the importance of early detection of serious medical conditions, like the ones included on the newborn screen.  This bill will ensure that as advances in newborn screening are made, that Indiana will be ready to respond and apply best practices to help keep babies healthy and safe.   Thank you, and I’m happy to answer any questions at this time.

**Evaluation:**

1. Condition with serious health effects if not detected at time of birth
2. Is there a safe and effective treatment available to all
3. Testing is feasible, accurate, available on large scale

**Nomination pathway**

Form online à Committee for evaluation à Voting à IPQUIC governing council à health commissioner

**RUSP** (Recommended uniforming screening panel).  National guideline through Dept of Health and Human Services.