

Dear Committee Members,

I am writing in reference to HB 2563 regarding newborn screening for Krabbe Disease.

My niece and her husband's 14 month old..Jackson Cruz Garcia from Lawrenceville Georgia..passed away from this horrible, horrible disease on October 21, 2016.

The fact that Krabbe disease was not among those tested when he was born on August 9, 2015, is incredibly disheartening to those of us and others which this disease has impacted.

He was a healthy four month old, who suddenly became so very ill.

To know that his parents could've had information regarding this disease when he was tested...but NO testing was done.

So..instead they watched their child die from Krabbe. He was seen by so many specialists and they took him to Children's hospital in Pittsburgh. They kept fighting to keep their baby alive!

But..it was too late to help Jackson.

The love and phenomenal caring from his parents was heartbreaking to watch, as an Aunt knowing there was nothing to be done...all because Jackson was not tested for Krabbe Disease.

As a parent how can we allow...NOT to include testing for Krabbe on this bill!!

As a human being how can you NOT!!

You CAN AND YOU SHOULD!!

These babies need your help!

These parents need your help!

These grandparents need your help!

These aunts and uncles need your help!

Please listen to the families and friends of these children!

As an aunt of Jackson Cruz Garcia I thank you for considering HB 2563.

Sincerely,

Patricia Eagles

Sent from my iPad