

The Honorable Shane E. Pendergrass
Chair, Health and Government Operations
241 Taylor House Office Building
6 Bladen Street
Annapolis, MD 21401

The Honorable Joseline A. Pena-Melnyk
Vice Chair, Health and Government Operations
241 Taylor House Office Building
6 Bladen Street
Annapolis, MD 21401

Re: Testimony of Jennifer Payne 1/19 at 2:30 p.m.

Madame Chair, my name is Jennifer Payne, and I am a constituent of District 13. As an Ambassador for the greater Maryland Rare disease community, I thank you the opportunity to share my testimony with you today in support of HB109.

My Connection: Maryland, Dept. of Health and Mental Hygiene, Preventative Medicine Administration

It is with deep and heartfelt gratitude for the State of Maryland's Newborn Screening (NBS) Program that I come to you today as an adult beneficiary and among the first diagnosed in the State with the rare genetic disorder, phenylketonuria (PKU) in 1973. Thanks to NBS, timely diagnosis and early treatment spared me a lifetime of institutional care. Because of my age, only I can offer you "living" testimony to the power of prevention - with my historical perspectives on growing up in Maryland's PKU Program¹ (early days) and speak directly to the legislative impact of this powerful public health policy tool that saved my life - and my children's lives.

I ask you to Reaffirm this Commitment: with *passage of HB109* because **preventing** devastating illnesses and diseases before they become too serious and too costly to treat benefits all Americans to live well, to stay healthy, and to freely live their lives.

Historical Framing of Testimony

PKU: Early detection and early treatment are critical for the clinical management of PKU, the effects (for which the brain and central nervous system are the target organs of damage) stem from a deficiency or inability of the liver to metabolize phenylalanine (phe), a building block of protein found in virtually every food. Given my medical history and risk with PKU, knowing the accumulation of phe is also teratogenic to offspring of untreated mothers, I can proudly say my children are all healthy and alive thanks to NBS.

Benefits and Impact of the Recommended Uniform Screening Panel (RUSP) Alignment: As I have demonstrated, Maryland's participation in RUSP alignment is critical to saving lives and to ensuring a

¹ See enclosed: NCATS NIH Video Profile. Payne, Jennifer; July 2016, <https://youtu.be/btSQQYcxnjK> quoted in NIH National Center for Advancing Translational Sciences, Genetic and Rare Diseases Information Center (GARD) website, <https://rarediseases.info.nih.gov/diseases/7383/phenylketonuria> In this NCATS Video Profile, Jennifer Payne discusses living with phenylketonuria (PKU). Left untreated, PKU results in psychological disorders, neurological deterioration, mental illness and brain damage. Dietary management and access to medical foods are a critical part of PKU care.

IN SUPPORT OF HB109 REQUIRING THE NEWBORN SCREENING PROGRAM IN THE MARYLAND DEPT. OF HEALTH
TO REQUIRE TESTING FOR EACH CONDITION LISTED BY THE RECOMMENDED UNIFORM SCREENING PANEL (RUSP)

continuation in these effective health programs. In addition, having the necessary resources available to fund the conditions added to RUSP is as equally critical for they impacted our family with dire and direct consequences. (See attached Appendix for your reference).

Conclusion: Speaking professionally and personally, when it comes to public health - the mission we share is one in the same. It comes down to saving lives. Thank you for the opportunity to speak in support of HB109.

/s/

Jennifer Weiland Payne, PharmD, MAPP
Independent Advocate, Adult with PKU
7115 John Calvert Ct
Elkridge, MD 21075
443-535-5322
pkupioneer@gmail.com

Enclosed:

NCATS NIH Video Profile. Payne, Jennifer; July 2016, <https://youtu.be/btSQQYcxnjik> quoted in NIH National Center for Advancing Translational Sciences, Genetic and Rare Diseases Information Center (GARD) website, <https://rarediseases.info.nih.gov/diseases/7383/phenylketonuria>

Under Separate Attachment:

Appendix: A dialogue with Carole Weiland, United States Senator Paul Sarbanes, and the State of Maryland illustrating the impact of withdrawing federal funding from Maryland's NBS program circa 1982.