Senate Bill 2224-In Support Sixty-seventh Legislative Assembly Human Services Committee January 25, 2021

Good morning Chairman Lee, Vice Chair Roers, and Human Services Committee members,

My name is Joan Connell. As a pediatrician and member of the Medicaid Medical Advisory Committee, I am requesting a Do-Pass for Senate Bill 2224. Passage of this bill would provide reimbursement by Medicaid for a smattering of metabolic supplements that are necessary for treatment of metabolic diseases but currently ineligible for reimbursement by Medicaid. While there are few metabolic supplements on this list, and few diseases with a very small number of patients, both points in which passage of this bill would result in a relatively insignificant increase in Medicaid expenditures, the economic impact on patients and their families is sizable. Patients and their providers have previously attempted alternative avenues for obtaining Medicaid reimbursement for these necessary treatments, including submission of appeals, completion of SFN 905 Medicaid forms, and recognition of this as a necessary service with subsequent reimbursement through Medicaid's EPSDT program, all to no avail. Hence, these patients are relying on your legislative efforts so that Medicaid fulfills its obligation to provide necessary treatments to those who qualify. Below is a table that lists the current metabolic supplements necessary for patients but uncovered by Medicaid. While I am in clinic seeing patients so unable to be here with you today, I am available via this email to answer any questions you may have regarding this issue that is so important for this subset of patients.

Cystic Fibrosis Specific Supplements: These vitamins contain the appropriate dosing for people with cystic fibrosis and other related fat- malabsorption conditions (these are needed in higher quantities than standard vitamins) >150% RDA MVW Complete Formulation	Metabolic Condition Supplements: These supplements are necessary for quality of life for people affected with a metabolic condition. The dosing is often greater than if the general population was ingesting as a supplement. Not taking these is not an option for people with these conditions. Alpha lipoic acid (fatty acid)	
(D3000 Chewables, D3000 Softgels, D5000 Softgels)		
AquADEKs	Betaine (amino acid)	
Vitamax	Biotin (Vitamin)	
ChoiceFul	B12 (Cobalamin)injections (vitamin that impacts fatty and amino acid metabolism)	
Libertas ABDEK	Coenzyme Q	
	Creatine monohydrate(treatment of impaired production of creatine)	
	Carnitine	
	Folic Acid	

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	Hydroxocobalamin (B12 <sub>a</sub> ) (tx of fatty		
	acid disorders)		
	Levocarnitine		
	Pyridoxine (B6) (regulation of the		
	balance of amino acids)		
	Riboflavin		
	Thiamine(B1)(metabolism of glucose)		
AMINO ACID			
SUPPLEMENTATION:			
Alanine	L-Alanine	Phenylalanine	L-
		-	Phenylalanine
Arginine*	L-Arginine*	Proline*	L-Proline*
Asparagine	L-Asparagine	Serine*	L-Serine*
Aspartic acid	L-Aspartic acid	Threonine	L-Threonine
Cystine*	L-Cystine*	Tryptophan	L-Tryptophan
Glutamic acid	L-Glutamic acid	Tyrosine*	L-Tyrosine*
Glutamine*	L-Glutamine*	Valine	L-Valine

\*-conditional amino acids, usually not essential except in times of illness or stress