

PKU Registry
Optional tool for use in collecting information

Survey	Information Requested	Information to be entered
Contact Information	Nutritionist contact information	
Demographics	Annual household income	
Diagnosis	Date of diagnosis	
	Lab units used for diagnostic phe level	mg/dl or umol/l
Genetics	PAH mutations known?	
	affected individual	
	mother	
	father	
Treatment/Diet	Current medical food (formula)	
	Amount and frequency	
	Types of low protein foods used	
	Current weight	
	Current height	
	Highest phe level and date	
	Lowest phe level and date	
Medical History	Ever had a serious illness?	
	type	
	date	
	treatment	
	Ever diagnosed with neurological illness?	
	type	
	date	
	treatment	
	Diagnosed with dermatologic (skin) problem?	
	type	
	date	
	treatment	
	Ever diagnosed with eczema?	
	date	
	treatment	
	Ever diagnosed with hyperactivity?	
	date	
	treatment	
	Ever diagnosed with ADD/ADHD?	
	date	
	treatment	

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Medical History – cont.	Ever diagnosed with autism spectrum disorder?	
	date	
	treatment	
	Ever diagnosed with psychiatric/psychological illness?	
	date	
	treatment	
	Tested for bone density?	
	date	
	Ever have broken bones?	
	date	
	Ever experienced stress?	
	at what age	
	Ever experienced depression?	
	At what age	
Education	Ever had an IQ test?	
	Upload results	
Female Repr Health	Age at first menstruation	
Maternal PKU	Date of positive pregnancy test	
	OB name and contact information	
	Weight at time of pregnancy	
	Blood phe during 1 st trimester	
	Blood phe during 2 nd trimester	
	Blood phe during 3 rd trimester	
	Infant’s birth weight and length	
	Infant’s head circumference	
	APGARs	
Insurance	Approx out of pocket spending for food, formula and meds - annually	
Other notes		

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