

ERADICATION OF DEATH BY ZIP CODE

SAVE OUR BABIES

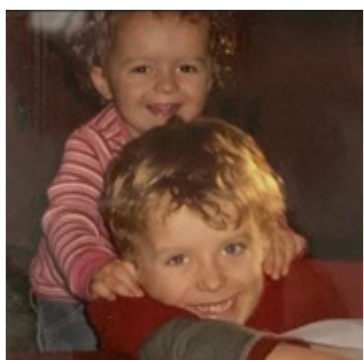


How does your state measure up? See the reverse page for the RUSP implementation state score card...

“Our son, Shane, was born January 26, 2018. Around six months old, Shane slowly stopped being the energetic, active baby he once was. After over four months of looking for answers, Shane finally was diagnosed with SMA – Type II. We learned that New Jersey had introduced a bill adding SMA to the newborn screening panel just 10 days before Shane was born. If newborn screening for SMA actually had been implemented at that time, Shane would have been diagnosed and treated before he lost most of his motor function. In January 2020, the law was passed requiring SMA to be added to the newborn screening panel, but there have been numerous delays in implementation. Early diagnosis and treatment of SMA is imperative. In pre-symptomatic cases, it can mean a life without symptoms. In more severe cases, it can mean life or death. Where you are born should never dictate whether you live.”



- Regina M. Philipps, New Jersey



Aidan lost his battle with X-ALD at age 7. This appropriations language acknowledges that the slow implementation of RUSP approved conditions means over 1,000 babies will needlessly die or face permanent disability – simply based on which state they were born in.

To honor Aidan and the thousands of babies that have lost their lives to a late diagnosis, Congress should provide \$15 million annually in streamlined CDC funding directly to states for costs associated with implementing newborn screening for all RUSP conditions so every state has complete newborn screening by 2025, saving thousands of lives and medical costs.

	Screens for this many conditions	Births/Year	ALD	MPS I	Pompe	SMA	How many of 4 RUSP conditions?
Alabama	46	60,000	No	No	No	No	0
Alaska	53	11,500	No	No	No	No	0
Arizona	31	85,000	No	No	No	No	0
Arkansas	32	39,000	No	No	No	No	0
California	64	500,000	Yes	Yes	Yes	Yes	4
Colorado	45	67,000	No	No	No	Yes	1
Connecticut	66	36,000	Yes	No	No	Yes	2
Delaware	55	11,000	Yes	Yes	Yes	Yes	4
DC*	62	10,000	Yes	Yes	Yes	No	3
Florida	56	225,000	Yes	Yes	Yes	Yes	4
Georgia	33	130,000	Yes	Yes	Yes	Yes	4
Hawaii	49	18,000	No	No	No	No	0
Idaho	48	23,000	No	No	No	No	0
Illinois	65	155,000	Yes	Yes	Yes	Yes	4
Indiana	56	84,000	No	Yes	Yes	Yes	3
Iowa	53	40,000	No	No	No	Yes*	1
Kansas	34	38,000	No	Yes	Yes	Yes	3
Kentucky	59	56,000	Yes	Yes	Yes	Yes	4
Louisiana	34	63,000	No	No	No	No	0
Maine	52	13,000	Yes	Yes	Yes	Yes	4
Maryland	61	74,000	No	Yes	Yes	Yes	3
Massachusetts	66	71,000	Yes*	Yes*	Yes*	Yes*	4
Michigan	58	114,000	Yes	Yes	Yes	Yes	4
Minnesota	61	70,000	Yes	Yes	Yes	Yes	4
Mississippi	63	38,000	No	Yes	Yes	Yes	3
Missouri	76	75,000	No	Yes	Yes	Yes	3
Montana	32	12,000	No	No	No	No	0
Nebraska	37	27,000	Yes	Yes	Yes	No	3
Nevada	57	36,000	No	No	No	No	0
New Hampshire	39	12,300	Yes	Yes	Yes	No	3
New Jersey	57	103,000	No	Yes	Yes	No	2
New Mexico	49	25,000	No	No	No	No	0
New York	60	250,000	Yes	Yes	Yes	Yes	4
North Carolina	37	121,000	No	No	No	No	0
North Dakota	53	12,000	No	No	No	No	0
Ohio	38	140,000	No	Yes	Yes	No	2
Oklahoma	54	53,000	Yes	Yes	Yes	Yes	4
Oregon	53	46,000	No	Yes	Yes	No	2
Pennsylvania	38	140,000	Yes	Yes	Yes	Yes	4
Rhode Island	35	11,000	Yes	Yes	Yes	Yes	4
South Carolina	54	58,000	No	No	No	No	0
South Dakota	50	12,500	No	No	No	No	0
Tennessee	71	81,000	Yes	Yes	Yes	Yes	4
Texas	56	400,000	Yes	No	No	No	1
Utah	53	51,000	Yes	No	No	Yes	2
Vermont	36	6,000	Yes	Yes	Yes	Yes	4
Virginia	33	103,000	No	Yes	Yes	No	2
Washington	37	91,000	Yes	Yes	Yes	Yes	4
West Virginia	39	20,000	No	No	No	Yes	1
Wisconsin	48	67,000	No	No	No	Yes	1
Wyoming	52	7,500	No	No	No	Yes	1
		3,991,800					