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