

Genetics and Newborn Screening Advisory Council Statistics

*Live Birth Data is provisional	2021	2022	2023	2024	2025*	2026	2027	2028	2029	2030
<b>LIVE BIRTHS</b>	<b>216,536</b>	<b>224,611</b>	<b>221,742</b>	<b>224,733</b>	<b>224,280</b>					
Number of newborns screened	215,758	223,445	220,769	223,826	223,054					
Percentage screened	99.64%	99.48%	99.56%	99.60%	99.45%					
SW Unsatisfactory Specimen Rate	1.77%	1.45%	1.29%	1.12%	0.99%					
Hospital Unsat Rate	1.52%	1.20%	1.07%	0.86%	0.73%					
SW Transit time (%>3days)	21.69%	19.53%	14.79%	13.62%	11.71%					
Hospital Transit (%>3days)	20.11%	17.87%	13.35%	12.31%	10.42%					
# of specimens submitted	265,443	270,554	266,910	269,926	268,965					
<b>PRESUMPTIVE POSITIVES and BORDERLINE REFERRALS</b>										
<b>Congenital Hypothyroidism</b>	<b>157</b>	<b>164</b>	<b>204</b>	<b>202</b>	<b>161</b>					
TSH Borderline	3,782	4,387	3,281	3,499	4,543					
<b>Congenital Adrenal Hyperplasia</b>	<b>15</b>	<b>20</b>	<b>28</b>	<b>27</b>	<b>33</b>					
CAH >24 hrs >2500g	95	120	114	147	162					
CAH <24 hrs >2500g - Early	169	203	190	257	276					
CAH <2500g Age-N/A - Low wt	30	55	31	56	49					
<b>Galactosemia</b>	<b>73</b>	<b>75</b>	<b>52</b>	<b>49</b>	<b>108</b>					
GALT Borderline	52	54	28	38	65					
<b>Sickle Cell Disease</b>	<b>269</b>	<b>283</b>	<b>252</b>	<b>230</b>	<b>228</b>					
<b>MS/MS</b>	<b>482</b>	<b>550</b>	<b>429</b>	<b>432</b>	<b>437</b>					
MS/MS Borderline	2,316	2,347	2,482	2,359	2,427					
<b>Biotinidase Deficiency</b>	<b>14</b>	<b>12</b>	<b>12</b>	<b>23</b>	<b>17</b>					
Bio Borderline	23	17	14	36	29					
<b>SCID</b>	<b>96</b>	<b>74</b>	<b>53</b>	<b>9</b>	<b>49</b>					
SCID Borderline	38	161	178	150	274					
<b>Cystic Fibrosis</b>	<b>805</b>	<b>1,223</b>	<b>1,146</b>	<b>1,338</b>	<b>270</b>					
Single Variant Detected	CF Single Variant Letters began 1/13/2025				988					
Ultra-Hi IRT/No Variants in NICU	745	804	549	740	690					
<b>Partial Unsatisfactory</b>	<b>205</b>	<b>163</b>	<b>200</b>	<b>256</b>	<b>186</b>					
<b>GAMT</b>	GAMT screening began 1/21/25				1					
GAMT Borderline	GAMT screening began 1/21/25				14					
<b>X-ALD</b>	<b>37</b>	<b>51</b>	<b>47</b>	<b>87</b>	<b>68</b>					
<b>MPS I</b>	<b>3</b>	<b>5</b>	<b>4</b>	<b>7</b>	<b>1</b>					
<b>MPS II</b>	MPS II screening began 7/1/24			4	3					
<b>Pompe</b>	<b>24</b>	<b>28</b>	<b>30</b>	<b>30</b>	<b>34</b>					
<b>SMA</b>	<b>15</b>	<b>11</b>	<b>12</b>	<b>16</b>	<b>19</b>					
<b>Presumptive Positives</b>	<b>1,990</b>	<b>2,496</b>	<b>2,269</b>	<b>2,454</b>	<b>1,429</b>					
<b>Borderlines</b>	<b>7,455</b>	<b>8,311</b>	<b>7,067</b>	<b>7,538</b>	<b>8,715</b>					
<b>TOTAL</b>	<b>9,445</b>	<b>10,807</b>	<b>9,336</b>	<b>9,992</b>	<b>10,144</b>					
<b>Hearing Refers</b>	<b>8,556</b>	<b>9,283</b>	<b>8,797</b>	<b>8,670</b>	<b>8,992</b>					
<b>Pulse Oximetry/CCHD Fails</b>	<b>233</b>	<b>269</b>	<b>292</b>	<b>317</b>	<b>464</b>					

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<b>CONFIRMED POSITIVES</b>										
<b>Congenital Hypothyroidism</b>	68	81	76	103	69					
CH diagnosed thru BDL	9	15	22	15	16					
<b>Congenital Adrenal Hyperplasia</b>	10	9	12	11	7					
<b>Galactosemia (G/G)</b>	6	0	3	3	6					
Variant	32	32	16	13	32					
<b>Sickle Cell Hb S/S</b>	115	148	120	104	81					
<b>Sickle Cell Hb S/C</b>	71	74	63	71	39					
<b>Sickle Cell Hb S/A</b>	13	10	8	7	9					
<b>MS/MS (including PKU)</b>	37	33	29	35	34					
<b>MS/MS secondary disorders</b>	11	17	19	15	10					
<b>Biotinidase Deficiency</b>	3	0	7	7	2					
Partial	5	5	3	7	6					
<b>Cystic Fibrosis 2 Variants</b>	29	29	23	36	29					
<b>Cystic Fibrosis 1 Variant</b>	7	0	0	0		Single variant results no longer referred as of 1/13/2025				
<b>Cystic Fibrosis High IRT; 0 Variants</b>	0	0	0	0	0					
<b>CRMS</b>	15	52	80	114	84					
<b>SCID</b>	5	2	4	2	2					
<b>GAMT</b>	GAMT screening began 1/21/25				0					
<b>X-ALD</b>	11	12	16	17	10					
<b>Pompe</b>	5	7	9	11	3					
<b>MPS I</b>	1	2	1	1	1					
<b>MPS II</b>	MPS II screening began 7/1/24			0	0					
<b>SMA</b>	15	10	11	15	14					
<b>TOTAL</b>	<b>468</b>	<b>538</b>	<b>522</b>	<b>587</b>	<b>454</b>					
<b>Hearing loss ID'd thru NBS</b>	<b>320</b>	<b>346</b>	<b>343</b>	<b>353</b>	<b>253</b>					
<b>CMV Positives</b>	CMV screening began 1/1/23		<b>125</b>	<b>133</b>	<b>126</b>					
<b>CCHD - cardiac</b>	9	25	29	17	5					
<b>CCHD - secondary cardiac</b>	38	50	57	62	51					
<b>CCHD - non-cardiac/other</b>	126	108	125	122	141					
<b>CCHD - no disease found</b>	60	83	70	70	49					
<b>TOTAL</b>	<b>47</b>	<b>75</b>	<b>86</b>	<b>79</b>	<b>56</b>					
<b>Physician Requests (CMS)</b>	1,024	1,250	1,174	1,591	1,687					
FNSR Registered Users	5,055	6,427	7,677	9,042	10,383					