Genetics and Newborn Screening Advisory Council Statistics

*Live Birth data is provisional	2021	2022	2023	2024	2025*	2026*	2027	2028	2029	2030
LIVE BIRTHS	**216,536**	**224,611**	**221,742**	**224,733**	**224,329**	*				
Number of newborns screened	215,758	223,445	220,769	223,826	223,054	104,785				
Percentage screened	99.64%	99.48%	99.56%	99.60%	99.43%	*				
SW Unsatisfactory Specimen Rate	1.77%	1.45%	1.29%	1.12%	0.99%	0.72%				
Hospital Unsat Rate	1.52%	1.20%	1.07%	0.86%	0.73%	0.48%				
SW Transit time (%>3days)	21.69%	19.53%	14.79%	13.62%	11.71%	11.64%				
Hospital Transit (%>3days)	20.11%	17.87%	13.35%	12.31%	10.42%	10.26%				
# of specimens submitted	265,443	270,554	266,910	269,926	268,965	126,844				
PRESUMPTIVE POSITIVES and BORDERLINE REFERRALS										
Congenital Hypothyroidism	157	164	204	202	163	87				
TSH Borderline	3,782	4,387	3,281	3,499	4,550	2,336				
Congenital Adrenal Hyperplasia	15	20	28	27	33	14				
CAH >24 hrs >2500g	95	120	114	147	162	96				
CAH <24 hrs >2500g - Early	169	203	190	257	276	134				
CAH <2500g Age-N/A - Low wt	30	55	31	56	50	27				
Galactosemia	73	75	52	49	109	48				
GALT Borderline	52	54	28	38	66	41				
Sickle Cell Disease	269	283	252	230	228	96				
MS/MS	482	550	429	432	452	191				
MS/MS Borderline	2,316	2,347	2,482	2,359	2,449	1,134				
Biotinidase Deficiency	14	12	12	23	18	6				
Bio Borderline	23	17	14	36	28	10				
SCID	96	74	53	9	49	12				
SCID Borderline	38	161	178	150	274	80				
Cystic Fibrosis	805	1,223	1,146	1,338	270	131				
Single Variant Detected	CF Single Variant Letters began 1/13/2025				988	372				
Ultra-Hi IRT/No Variants in NICU	745	804	549	740	690	341				
Partial Unsatisfactory	205	163	200	256	186	33				
GAMT	GAMT screening began 1/21/25				1	1				
GAMT Borderline	GAMT screening began 1/21/25				15	5				
X-ALD	37	51	47	87	68	10				
MPS I	3	5	4	7	1	0				
MPS II	MPS II screening began 7/1/24			4	4	0				
Pompe	24	28	30	30	37	15				
SMA	15	11	12	16	19	8				
Presumptive Positives	1,990	2,496	2,269	2,454	1,452	619				
Borderline	7,455	8,311	7,067	7,538	8,746	4,237				
TOTAL	**9,445**	**10,807**	**9,336**	**9,992**	**10,198**	**4,856**				
Hearing Refers	8,556	9,283	8,797	8,670	8,992	3,917				
Pulse Oximetry/CCHD Fails	233	269	292	317	461	199				

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LIVE BIRTHS	**216,536**	**224,611**	**221,742**	**224,733**	**224,329**	*				
CONFIRMED POSITIVES										
Congenital Hypothyroidism	68	81	76	103	77	39				
CH diagnosed thru BDL	9	15	22	15	15	0				
Congenital Adrenal Hyperplasia	10	9	12	11	8	7				
Galactosemia (G/G)	6	0	3	3	6	2				
Variant	32	32	16	13	38	11				
Sickle Cell Hb S/S	115	148	120	104	113	35				
Sickle Cell Hb S/C	71	74	63	72	54	16				
Sickle Cell Hb S/A	13	10	8	7	11	3				
MS/MS (including PKU)	37	33	29	35	39	13				
MS/MS secondary disorders	11	17	19	15	11	5				
Biotinidase Deficiency	3	0	7	7	3	0				
Partial	5	5	3	7	8	3				
Cystic Fibrosis 2 Variants	29	29	23	36	37	9				
Cystic Fibrosis 1 Variant	7	0	0	0	Single variant results no longer referred as of 1/13/2025					
Cystic Fibrosis High IRT; 0 Variants	0	0	0	0	0	0				
CRMS	15	52	80	114	106	21				
SCID	5	2	4	2	2	0				
GAMT	GAMT screening began 1/21/25				0	1				
X-ALD	11	12	16	17	10	0				
Pompe	5	7	9	14	10	1				
MPS I	1	2	1	3	1	0				
MPS II	MPS II screening began 7/1/24			2	2	0				
SMA	15	10	11	15	15	5				
TOTAL	**468**	**538**	**522**	**595**	**566**	**171**				
Hearing loss ID'd thru NBS	**320**	**346**	**343**	**353**	**253**	**73**				
CMV Positives	CMV screening began 1/1/23		**125**	**133**	**126**	**59**				
CCHD - cardiac	9	25	29	18	16	1				
CCHD - secondary cardiac	38	50	57	63	90	48				
CCHD - non-cardiac/other	126	108	125	126	209	72				
CCHD - no disease found	60	83	70	80	78	25				
TOTAL	**47**	**75**	**86**	**81**	**106**	**49**				
Physician Requests (CMS)	1,024	1,250	1,174	1,591	1,687	807				
FNSR Registered Users	5,055	6,427	7,677	9,042	10,383	10,966				