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**	*						
Number of newborns screened	215,758	223,445	220,769	106,106						
Percentage screened	99.64%	99.48%	99.56%	*						
SW Unsatisfactory Specimen Rate	1.77%	1.45%	1.29%	1.29%						
Hospital Unsat Rate	1.52%	1.20%	1.07%	0.99%						
SW Transit time (%>3days)	21.69%	19.53%	14.79%	13.28%						
Hospital Transit (%>3days)	20.11%	17.87%	13.35%	11.82%						
# of specimens submitted	265,443	270,554	266,910	128,587						
PRESUMPTIVE POSITIVES and BORDERLINE REFERRALS										
Congenital Hypothyroidism	167	163	204	93						
TSH Borderline	3,782	4,387	3,281	1,536						
Congenital Adrenal Hyperplasia	15	20	28	5						
CAH >24 hrs >2500g	95	120	114	55						
CAH <24 hrs >2500g - Early	169	203	190	75						
CAH <2500g Age-N/A - Low wt	30	55	32	22						
Galactosemia	72	74	52	12						
GALT Borderline	52	54	28	14						
Sickle Cell Disease	271	285	252	110						
MS/MS	483	552	431	173						
MS/MS Borderline	2,316	2,347	2,482	1,126						
Biotinidase Deficiency	14	13	12	12						
Bio Borderline	23	17	14	14						
SCID	95	74	53	3						
SCID Borderline	38	161	178	67						
Cystic Fibrosis	812	1,145	1,146	647						
Ultra-Hi IRT/No Variants in NICU	745	804	549	378						
Partial Unsatisfactory	205	163	200	110						
X-ALD	33	52	47	31						
MPS I	3	5	4	6						
MPS II	MPS II screening began 7/1/24			0						
Pompe	24	28	30	10						
SMA	15	11	12	4						
Presumptive Positives	2,004	2,422	2,271	1,106						
Borderline	7,455	8,311	7,068	3,397						
TOTAL	**9,459**	**10,733**	**9,339**	**4,503**						
Hearing Refers	8,535	9,259	8,761	3,953						
Pulse Oximetry/CCHD Fails	233	272	286	159						

*Live Birth Data is provisional	2021	2022	2023*	2024*	2025	2026	2027	2028	2029	2030
LIVE BIRTHS	**216,536**	**224,611**	**221,742**	*						
CONFIRMED POSITIVES										
Congenital Hypothyroidism	76	96	84	39						
CH diagnosed thru BDL	8	15	20	5						
Congenital Adrenal Hyperplasia	10	10	7	1						
Galactosemia (G/G)	6	0	3	1						
Variant	30	31	16	2						
Sickle Cell Hb S/S	114	145	112	29						
Sickle Cell Hb S/C	71	73	60	12						
Sickle Cell Hb S/A	13	9	8	4						
MS/MS (including PKU)	36	34	28	17						
MS/MS secondary disorders	11	17	18	5						
Biotinidase Deficiency	3	0	7	3						
Partial	4	5	3	3						
Cystic Fibrosis 2 Variants	29	28	23	13						
Cystic Fibrosis 1 Variant	7	0	0	0						
Cystic Fibrosis High IRT; 0 Variants	0	0	0	0						
CRMS	14	54	79	45						
SCID	5	2	4	0						
X-ALD	19	27	26	10						
Pompe	7	13	10	6						
MPS I	1	4	2	2						
MPS II	MPS II screening began 7/1/24			0						
SMA	15	11	11	3						
TOTAL	**501**	**594**	**538**	**202**						
Hearing loss ID'd thru NBS	**299**	**307**	**297**	**90**						
CMV Positives	CMV screening began 1/1/23		**124**	**53**						
CCHD - cardiac	7	23	13	8						
CCHD - secondary cardiac	36	49	39	23						
CCHD - non-cardiac/other	119	106	93	31						
CCHD - no disease found	54	85	44	21						
TOTAL	**43**	**72**	**52**	**31**						
Physician Requests (CMS)	1,024	1,250	1,174	854						
FNSR Registered Users	5,055	6,427	7,677	8,274						