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Decreasing Births and NICU Admissions for Congenital Anomalies in the United States, 2016-2023

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Abstract

Objectives: Evaluate trends in U.S. births and NICU admissions for congenital anomalies

Study Design: This population-based, cross-sectional study included all births with congenital anomalies in the U.S. from 2016 to 2023 from CDC WONDER. Trends in anomaly-associated NICU admissions and births were assessed.

Results: From 2016-2023, NICU admissions for anomalies decreased from 18.5 to 18 per 10,000 live births (annual percent change (APC), -0.4%; 95% CI, -0.7% to -0.2%). Admissions for gastroschisis showed the greatest decline; admissions for cyanotic congenital heart disease (CCHD) increased. NICU trends approximated birth trends for neonatal surgical anomalies, and not for non-surgical or life-limiting anomalies.

Conclusions: Births and NICU admissions for congenital anomalies declined modestly in the U.S. from 2016 to 2023 with births decreasing to a greater degree than NICU admissions. Anomaly-specific considerations such as need for neonatal surgical repair, comorbid diagnoses requiring NICU care, and parental goals of care may explain these differences.

Introduction

In the United States, 120,000 children are born each year with congenital anomalies, many requiring neonatal intensive care.[1] Neonates with congenital anomalies account for a substantial proportion of admissions to neonatal intensive care units (NICUs), often require lifelong multidisciplinary care, and are the leading cause of infant mortality.[2–4] From 2016-2023, U.S. NICU admission rates increased across all gestational ages and regions; however, trends in admissions attributable to congenital anomalies have not been described.[3,5] Recent data suggest an increase in admissions of infants with complex medical conditions to NICUs; however, the specific contribution of infants with congenital anomalies is not known.[6]

While hospital datasets provide critical information on the burden, management, and outcomes of infants with congenital anomalies, they lack the denominator of liveborn infants with anomalies and therefore cannot be used to calculate NICU admission rates among neonates with congenital anomalies.[7] Among infants with anomalies, the spectrum of care varies depending on the diagnosis, ranging from conditions almost universally requiring NICU care, to those for which NICU admission depends on the goals of care of the family, to anomalies that rarely require intensive care. Comparing the prevalence of congenital anomalies admitted to the NICU with that among liveborn infants is important for understanding how epidemiologic trends impact neonatal hospitalization, the NICU burden associated with specific anomalies and shifts in contemporary approaches to managing certain diagnoses.

Among infants born in the U.S. with congenital anomalies from 2016-2023, we sought to 1) evaluate and compare temporal trends in anomaly-associated NICU admissions per 10,000 live births compared to live birth anomaly prevalence, overall, and by anomaly, 2) evaluate trends in anomaly-specific NICU admission rates and anomaly proportion of NICU case-mix, overall, and by anomaly. Given the known rise in admissions of medically complex infants to NICUs, we hypothesized that NICU admissions for congenital anomalies and anomaly contribution towards NICU case-mix will have increased over time.

Methods

Study Population

For this population-based cross-sectional study, we obtained publicly available data from CDC WONDER (Wide-ranging ONline Data for Epidemiologic Research).[9] These data are derived from birth certificates for all live births in the U.S., collected and reported by states, and compiled by the National Center for Health Statistics (NCHS). We used the natality dataset from 2016–2023 to assess NICU admissions and the prevalence of congenital anomalies among live births. For each birth, information is available on abnormal conditions of the newborn, including the presence of congenital anomalies and NICU admission. NICU admission is defined as care in a facility staffed and equipped to provide continuous mechanical ventilatory support for a newborn, encompassing level III and IV NICUs.

We evaluated births for the twelve specific anomalies reported in CDC WONDER: anencephaly, spina bifida, gastroschisis, omphalocele, trisomy 21, chromosomal anomalies, congenital diaphragmatic hernia (CDH), cyanotic congenital heart disease (CCHD), cleft lip with or without palate, cleft palate alone, and hypospadias. CDC WONDER selects these defects because they are common, tracked by most states, and can be linked to potential environmental factors.

Definitions of each anomaly used by CDC WONDER are provided: *Anencephaly* is defined as partial or complete absence of the brain and skull and includes infants with a contiguous spine defect. *Spina bifida* encompasses both open and closed defects, including meningoceles. It does not include spina bifida occulta. *Confirmed* genetic conditions include *trisomy 21* as a unique entity, as well as the *chromosomal anomalies* that comprise ICD-10 codes Q91-99 (including trisomy 13, trisomy 18, Turner's syndrome, sex chromosomal abnormalities, monosomies and deletions of autosomes, and triploidy). *Cyanotic congenital heart disease (CCHD)* includes congenital heart defects which cause cyanosis: transposition of the great arteries, tetralogy of Fallot, pulmonary or pulmonic valvular atresia, tricuspid atresia, truncus arteriosus, total/partial anomalous pulmonary venous return with or without obstruction, coarctation of the aorta, hypoplastic left heart syndrome, and interrupted aortic arch. Data on *hypospadias* exclude female infants. *Omphalocele* excludes umbilical hernia. *Limb reduction defects* include the complete or partial absence of a portion of an extremity associated with failure to develop. *Cleft palate* includes clefts of the soft and hard palate. When present with a cleft lip, it is designated *cleft lip with or without palate*.

We calculated totals for all twelve anomalies by using the field, “any congenital anomaly checked” in the data query. This approach prevents double-counting infants who have multiple anomalies. For example, an infant with both trisomy 21 and CCHD would be counted once in the trisomy 21 total, once in the CCHD total, and once in the overall congenital anomaly total.

CDC WONDER provides de-identified, aggregate public-use data, and this project was deemed exempt from institutional review board review. Analyses and reporting of results were conducted in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.[9]

Study Outcomes

To calculate NICU admission and live birth prevalence rates of congenital anomalies, we used total live births for each year as the exposure. Our primary outcome was *NICU admission*, defined as the rate of congenital anomaly-associated NICU admissions per 10,000 live births, overall, and stratified by each anomaly. Our secondary outcomes were 1) live birth prevalence of anomalies, calculated as the number of congenital-anomaly births per 10,000 live births, 2) anomaly-specific NICU utilization rate, calculated as the percentage of anomaly births admitted to NICUs, overall, and by anomaly, and 3) anomaly proportion of NICU case-mix, calculated as anomaly-associated NICU admission per 1,000 NICU admissions.

Statistical analysis

We assessed temporal trends by examining annual rate estimates and line plots to evaluate absolute changes over time. We summarized relative changes in NICU admission trends using log-linear Poisson regression models to estimate annual percent change (APC) using yearly counts of cases as the outcome and the log of total live births as the offset. Anomaly-specific NICU admission rate trends were additionally modeled using the yearly counts of anomaly-affected NICU admissions as the outcome and anomaly live births as the offset. APC was calculated as the yearly average percent change in prevalence over time and was chosen to characterize trends, as it is comparable across different scales. Calendar year was modeled as a continuous predictor, and APC was calculated as $(\exp(\beta)-1) \times 100$, where β represents the estimated yearly change on the log scale. 95% confidence intervals for APCs were calculated using published reference methods.[10] Robust standard errors were used to account for potential overdispersion. We estimated APCs assuming a constant log-linear trend over time. Given the limited number of annual observations, analyses were considered exploratory.

Because under-ascertainment is a known problem with birth-certificate data, we additionally compared live birth prevalence estimates from CDC WONDER with the true population prevalence reported from states with robust birth defect registries for data benchmarking.[11]

Data analyses were performed using STATA 18 (StataCorp. 2023. *Stata Statistical Software. Release 19*. College Station, TX: StataCorp LLC).

Results

Between 2016 and 2023, ~29 million total U.S. live births and ~2.7 million NICU admissions were recorded in CDC WONDER. (**Supplemental Table 1**) Of these, 102,395 live births (0.5% of total live births) and ~55,325 total NICU admissions (0.19% of total live births) were reported to have one of the twelve congenital anomaly diagnoses. During the study period, both U.S. total live births and anomaly births decreased **(Figure 1a).** Total NICU admissions from all causes increased, while anomaly-associated NICU admissions decreased. (**Figure 1b**).

NICU Admissions for Anomalies

Table 1 shows NICU admission rate of congenital anomalies per 10000 live births. From 2016-2023, NICU admissions associated with congenital anomalies slightly decreased from 18.5 to 18 per 10000 live births, corresponding to an annual percent change of -0.45% (95% CI, -0.69% to -0.20%).

The largest relative decline in NICU admissions was observed for gastroschisis and limb-reduction defects. NICU admissions for spina bifida and hypospadias also decreased but to a lesser degree. In contrast, NICU admissions for CCHD increased over time, the only anomaly to display this trend. NICU admissions for trisomy 21 remained stable, while admissions for chromosomal anomalies showed a downward trend.

NICU Admissions vs. Birth Prevalence of Anomalies

Figure 2a shows line plots depicting NICU admission and birth prevalence trends per 10000 live births for each of the twelve anomalies as well as NICU utilization rates for each anomaly. Live birth prevalence trends for congenital anomalies are presented in **Supplemental Table 2.** As noted above, NICU admission trends decreased for gastroschisis and limb reduction defects and increased for CCHD.

For anomalies requiring neonatal surgical intervention such as abdominal wall defects, CDH, spina bifida, NICU admission rates approximate birth prevalence rates. Conversely, anomalies with variable need for either surgical correction during the neonatal period and/or intensive care showed significant differences between NICU and population prevalence.

Figure 2b and **2c** represent comparative APC trends in NICU admission vs. birth prevalence of anomalies in different ways. For most anomalies, NICU admission trends tracked closely with live birth trends with an overall decrease. Exceptions were chromosomal anomalies, where birth prevalence increased, but NICU admissions decreased, and cleft lip ± palate and cleft palate, which demonstrated declining live birth prevalence but rising NICU admissions.

Anomaly-specific NICU utilization rate

Overall, approximately 54% of infants born with congenital anomalies were admitted to NICUs. (**Figure 2a and Table 2**) 85% of infants born with abdominal wall defects, CDH, and spina bifida were recorded as

being admitted to NICUs. Sixty percent of infants with trisomy 21 were admitted to NICUs, while 50% of those with other chromosomal anomalies were admitted to NICUs. Anomalies such as hypospadias, cleft lip and palate, limb reduction defects, and anencephaly had lower NICU admission proportions, generally less than 35%.

Anomaly-specific NICU utilization rates remained stable overall. **(Table 2**). NICU utilization rates increased for abdominal wall defects, spina bifida, cleft palate, and cleft lip; and declined for chromosomal anomalies.

Anomaly proportion of NICU case-mix (Anomaly-associated NICU admission per 1000 NICU admissions)

Approximately 2% of NICU admissions annually in the U.S. were attributed to the twelve anomalies reported in CDC WONDER. (**Supplemental Table 3**) The proportion of NICU admissions associated with congenital anomalies declined for all but two anomalies, CCHD and anencephaly, where they remained stable. Gastroschisis admissions showed the largest decline, followed by limb reduction defects, and hypospadias, similar to the observed NICU admission trends for these conditions.

Comparison of Birth-Certificate Recorded Anomaly Prevalence to True Population Prevalence

Because under-reporting is a common challenge with birth certificate data, live birth prevalence estimates from our analysis were compared with estimates from studies using active birth defect registries for data benchmarking (**Supplemental Table 4)**.[11] Observed-to-expected prevalence ratios ranged from 0.15 to 0.53 across anomalies and reflect a combination of underreporting and exclusion of terminations and stillbirths in anomaly counts in CDC WONDER.

Discussion

This study provides a comprehensive analysis of NICU utilization trends for congenital anomalies contextualized against birth trends; to better understand how epidemiologic trends influence neonatal hospitalization patterns and to characterize the burden of congenital anomalies in U.S. NICUs. Our major conclusions are the following:

1. NICU admissions for anomalies declined nationally, even as NICU admissions from all causes increased over time. In alignment with this finding, anomalies accounted for a decreased proportion of the NICU case-mix over time.
2. Over half of infants born with the twelve reported congenital anomalies were admitted to the NICU, with expected wide variation in NICU utilization rates based on the type of anomaly.
3. The proportion of anomaly births admitted to the NICU remained relatively stable over time and likely reflects a combination of prenatal diagnosis and planned or averted NICU admission, neonatal delivery room management considerations, and for some anomalies, differences in parental goals of care.

4. NICU admission trends largely paralleled birth trends for surgical anomalies, but not for non-surgical or life-limiting anomalies.

Counter to our hypothesis, NICU admissions for anomalies decreased over time. Gastroschisis exhibited the greatest decline in NICU admissions, aligning with recent studies[CD1] .[12,13] The reason for this decline is likely multifactorial and has been attributed to declining maternal smoking and births among individuals less than 25 years old.[14,15] In contrast, CCHD was the only anomaly with rising NICU admissions[CD2] . This finding is consistent with recent studies showing an increased prevalence of congenital heart disease in regions with limited abortion access[CD3] .[16] In addition, universal newborn CCHD screening implemented in 2018 may permit greater neonatal detection of these diagnoses, although the impact of specific policies on year-to-year changes in prevalence was not evaluated in this study. [17]

NICU utilization rates varied widely between anomalies, with surgical anomalies having high NICU utilization rates. Due to differential need for NICU care between anomalies, NICU trends for anomalies did not uniformly mirror birth trends. For anomalies that universally require intensive neonatal care, usually for surgical repair, such as abdominal wall defects, NICU admissions closely tracked with birth trends. For CCHD, another group of patients who almost universally require intensive neonatal care, NICU admissions increased to a smaller degree as compared to the increase in live births. This may reflect optimized perinatal planning, including admission to specialized cardiac intensive care units rather than NICUs, and variable parental care decisions for severe lesions.[18,19] For anomalies with variable NICU trends, such as trisomy 21, NICU admission may be contingent on whether an infant has associated comorbidities such as cardiac defects, feeding difficulties, or airway compromise. NICU admission for hypospadias, which typically do not require intensive care when isolated, is likely to reflect other significant anomalies or perinatal complications necessitating intensive care.

Notably, NICU admission rates for chromosomal anomalies declined nationally even as births increased. Since trisomy 13 and 18 account for a substantial proportion of reported chromosomal anomalies, this finding may indicate a shift toward fewer NICU admissions for these diagnoses, even as recent literature suggests increased provision of intensive interventions for selected infants.[20] This finding must be interpreted in the context of certain limitations: CDC WONDER does not capture pregnancy terminations, stillbirths, or postnatal diagnoses made after discharge, therefore these estimates likely reflect prenatally diagnosed cases where pregnancy was continued that resulted in live birth and NICU admission; in addition, these diagnoses are often present in association with other midline defects, such as cleft lip and palate or congenital heart disease, which demonstrated an increasing NICU admission trend. A single-center review showed that about half of families with a liveborn infant with trisomy 13 or 18 choose to pursue NICU treatment for their child, which aligns with our results.[22] Our findings provide insight into the proportion of liveborn infants with severe chromosomal conditions who may be admitted to U.S. NICUs, a denominator that is not usually available in studies using inpatient datasets.[20-23]

Our results confirm the known under-reporting of conditions in birth certificate data, and the discrepancy in prevalence estimates of birth defects depending on the type of registry used. [32,33] Prevalence estimates in our study are substantially lower than the commonly reported prevalence for birth defects and are not meant to be interpreted as the actual population prevalence of these conditions.[11] Rather, our results can provide a benchmark for future studies on birth defect prevalence using birth certificate data. Notably, the high NICU admission rates for surgical anomalies, which almost always require NICU admission, such as gastroschisis or spina bifida, suggest that NICU admissions are usually captured when these anomalies are recorded on the birth certificate. Also, NICU admission proportions across the twelve reported anomalies make pragmatic sense from a neonatal perspective.

What are the broader implications of these findings? The interpretation of these trends should be considered alongside contextual factors such as the true prevalence of the anomaly in the population, the degree of change over time, and the overall severity of the anomaly. For more prevalent anomalies such as CCHD with high survival rates, a modest increase in prevalence may translate into substantial numbers of infants requiring lifelong cardiac care and follow-up.[16] For less prevalent anomalies such as CDH, changes may have more limited impact in specialized centers that provide care for these complex infants. Notably, although infants with congenital anomalies constituted a small percentage of the NICU case-mix overall in CDC WONDER, at level IV children's hospitals, these infants can constitute a significant proportion of the NICU caseload. For rare, life-limiting anomalies such as anencephaly, the impact on healthcare utilization may be limited as these patients have high mortality and short hospital stays, but they may require workforce planning to strengthen bereavement and palliative care services for families.[24] The availability of subspecialist pediatric services, including palliative care, is a limited resource in many areas.[25-27] From the perspective of affected children and families, these conditions can have lasting impacts on long-term health and quality of life, psychosocial well-being, school performance and interactions with peers, and caregiving and financial burdens.[28-31]

Limitations

Our study has several limitations. CDC WONDER relies on birth certificate data, which underreport or misclassify anomalies, particularly those diagnosed after birth. In addition, counts exclude stillbirths and pregnancy terminations, thereby underestimating anomalies such as chromosomal conditions detected on prenatal screening, which have higher termination rates. Only 12 anomalies are reported in CDC WONDER, and common anomalies such as club foot and ventricular and atrial septal defects, are not included. NICU burden of other anomalies commonly seen in NICU patients (e.g., tracheoesophageal fistula, anorectal malformations, bowel atresias, and other genetic malformations) is not reported. NICU admissions are not stratified by level of care (e.g., level III versus level IV), and infants requiring highly specialized surgical or cardiac care may be underrepresented. Annual percent change calculations in our analysis assume a constant log-linear change over time; however, several anomalies demonstrated non-linear or region-specific temporal patterns, suggesting that APC may oversimplify underlying trends. Our analysis assumes that underreporting is consistent across time. Despite these limitations, this study is

the first national-level comparison of live birth and NICU prevalence of congenital anomalies, highlighting differential NICU burden across anomalies.

Conclusions

Although NICU admissions from all causes increased over time, admissions attributable to congenital anomalies declined modestly from 2016 to 2023, with the greatest reduction in admissions for gastroschisis. In contrast, admissions for cyanotic congenital heart disease increased. The impact of these trends may be greater for more prevalent anomalies such as cyanotic congenital heart disease, and more limited for rare anomalies. Population trends may be useful for estimating NICU admissions for anomalies that consistently require intensive care; however, for non-surgical or life-limiting anomalies, NICU utilization reflects a complex interplay of prenatal diagnosis, perinatal planning, neonatal management strategies, institutional resources, and parental goals of care. As under-ascertainment remains an important limitation of birth certificate data, these findings should be validated using data from states with robust population-based birth defects registries that link birth defects cases to vital records and infant hospitalization data.

Abbreviations

NICU
neonatal intensive care unit
APC
annual percent change
CDH
congenital diaphragmatic hernia
CCHD
cyanotic congenital heart disease
CDC
Centers for Disease Control
WONDER
Wide-ranging ONline Data for Epidemiologic Research

Declarations

Declaration of generative AI and AI-assisted technologies in the manuscript preparation process

During the preparation of this work, the authors used Chat GPT, Open AI, for assistance with statistical code development for data analysis. All analyses were performed by the authors, who take full responsibility for the content. The authors reviewed and edited the output as needed and take full responsibility for the content of the published article.

CRediT Authors' Statement

Dr. Acharya conceptualized and designed the study, performed all data analyses, drafted the initial manuscript, and critically reviewed and revised the manuscript.

Drs. Cortezzo, Rholl, Fry, and Riddle contributed to study design and conception, and edited and revised the manuscript based on their subject matter expertise for important intellectual content.

Dr. Cabacungan contributed to study design and conception, independently verified analysis performed by Dr. Acharya, and critically reviewed and revised the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Tables

Tables 1-3 are available in the Supplementary Files section.

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Figures

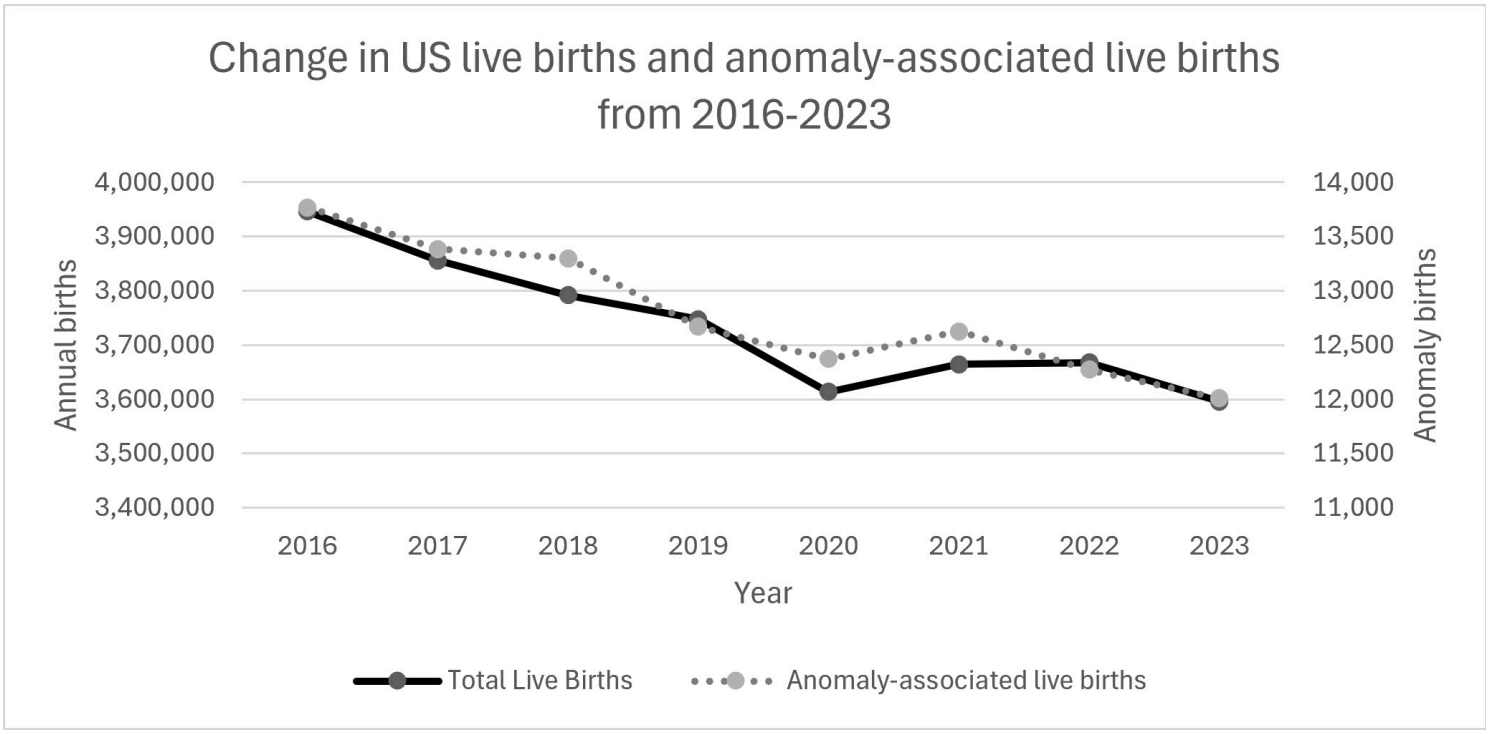


Figure 1

Figure 1a. Line plots showing trends in births and anomaly-associated births in the United States, 2016-2023

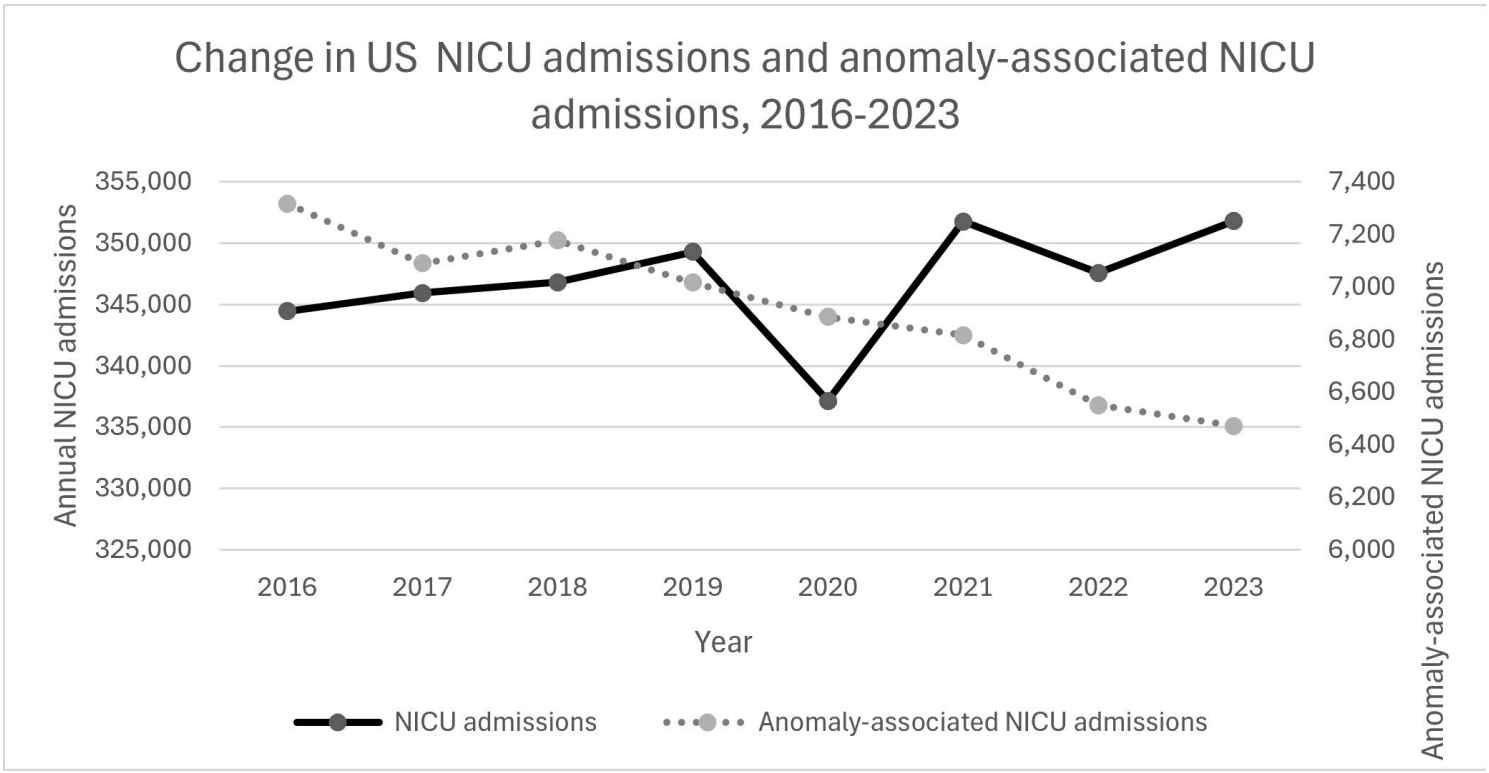


Figure 2

Figure 1b. Line plots showing trends in NICU admissions and anomaly-associated NICU admissions in the United States, 2016-2023

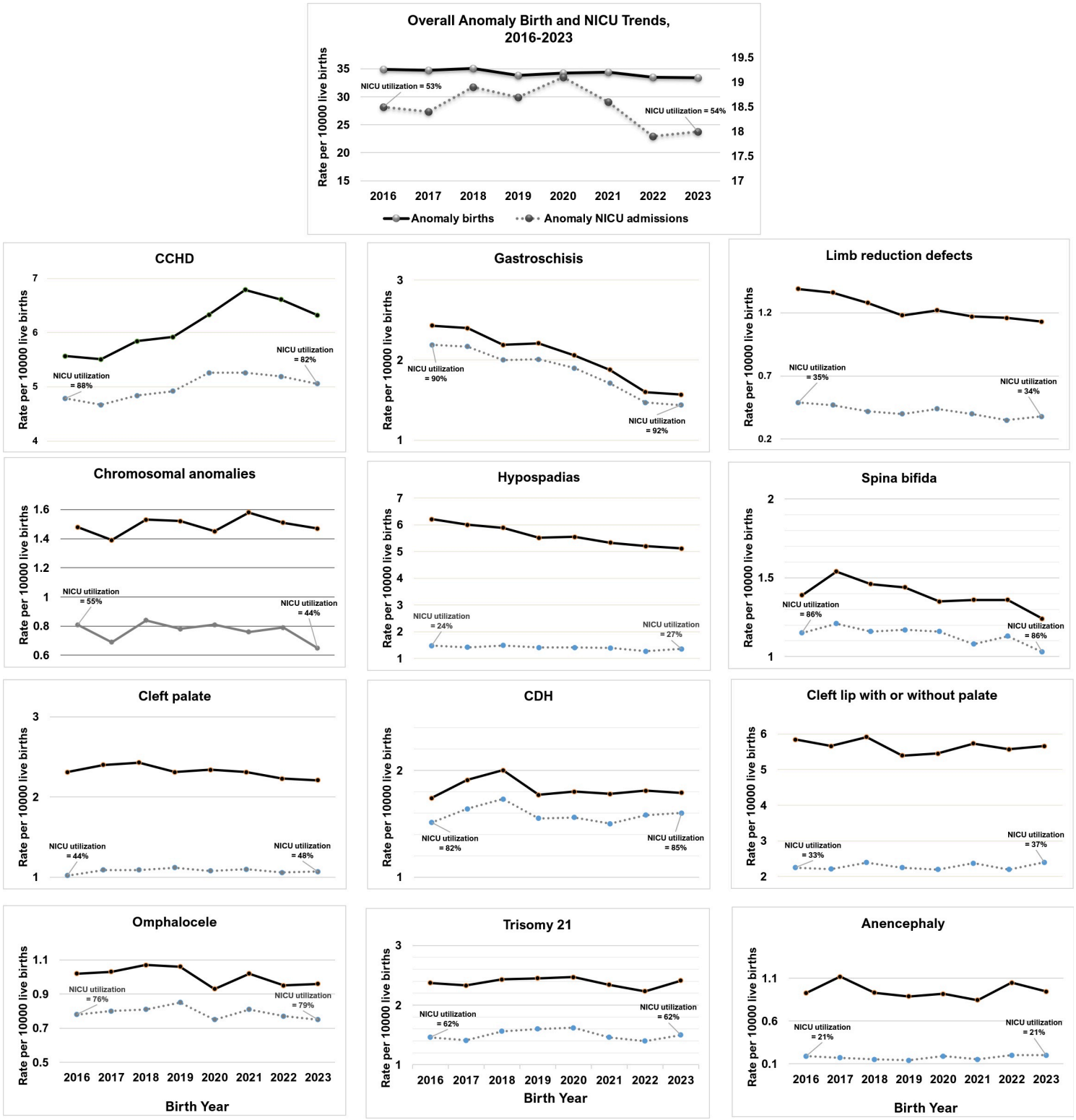


Figure 3

Figure 2a. Line Plots Comparing Birth Prevalence and NICU Admissions for Congenital Anomalies per 10,000 Live Births, 2016-2023

NICU utilization rates are shown as data labels

CDH=Congenital diaphragmatic hernia, CCHD=cyanotic congenital heart disease

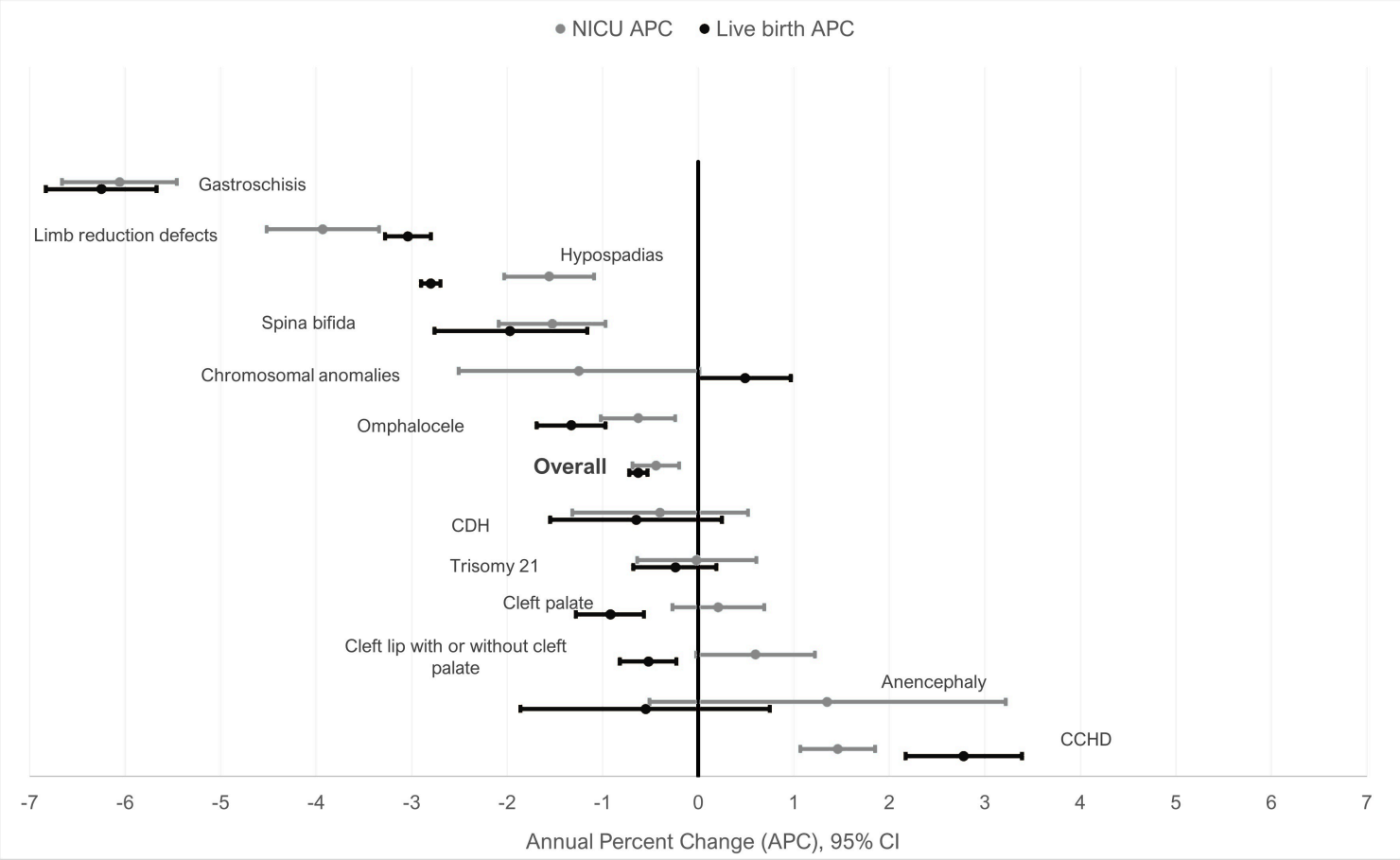


Figure 4

Figure 2b. Forest plot comparing Annual Percent Change in NICU admission vs. Birth Prevalence of Congenital Anomalies, 2016-2023

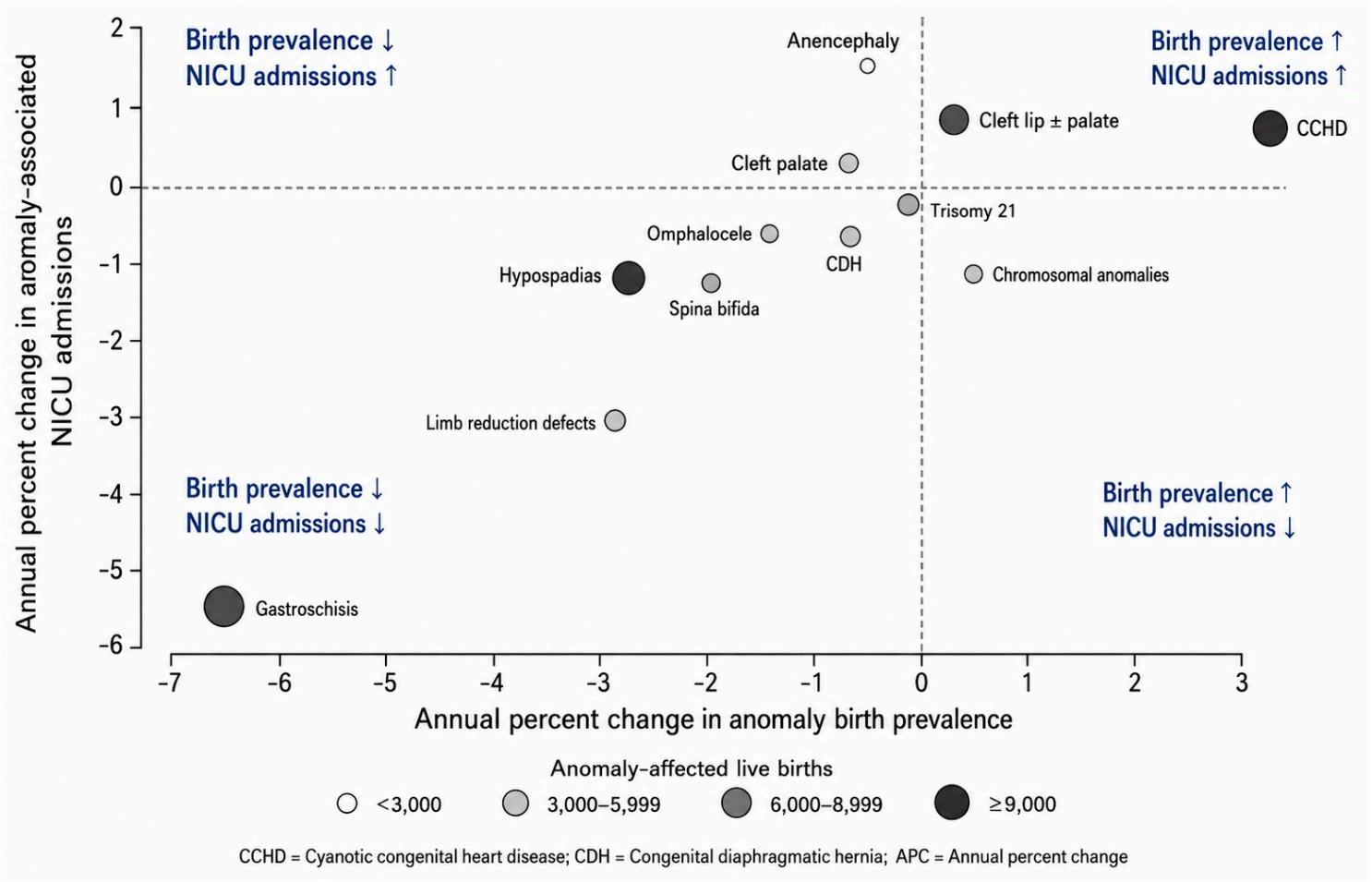


Figure 5

Figure 2c. Annual Percent Change in NICU Admission vs. Birth Prevalence of Congenital Anomalies in the United States, 2016-2023

Annual percent change in congenital anomaly prevalence versus annual percent change in neonatal intensive care unit (NICU) admission among anomaly-affected live births in the United States, 2016–2023. Bubble size and color indicate the number of anomaly-affected live births, with darker and larger circles representing higher birth counts. Dashed lines denote zero annual percent change.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Table1.docx
- Table2.docx
- SupplementalTable1.docx
- SupplementalTable2.docx
- SupplementalTable3.docx

- SupplementalTable4.docx