

Imagine...
*being born
without the ability
to breathe*

An open letter to the Women's Congressional Caucus Saving Infant lives

March 12, 2025

Dear Congresswomen, Senators;

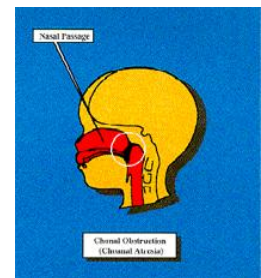
As I write this letter I am profoundly alarmed dismayed, even outright angry by recent findings of profound government waste, fraud, and abuse discovered by the Department Of Government Efficiency, (DOGE). But what about incidences where government should be investing funds to prevent human tragedy and deaths of newborn infants?

A mother whose three week old newborn infant, has just recently been diagnosed with unilateral choanal atresia. She is having difficulty with breastfeeding and is seeking help. She has been repeatedly been told by doctors her baby has allergies. Once diagnosed weeks or months later, her doctors informed her that surgical intervention should be done when her child is a year old or school age. They have no idea of the risk they are putting that baby in, nor the heartbreak and emotional distress they are putting the mother through, much less the child. Every mother who contacts us has this same story. We have put her in contact with another parent through our Parent-To-Parent 'Angel Network' for help. If I share this information with her it would profoundly increase her stress level.

Her baby does not need to be treated this way

According to NIH/NICH and CDC data, each year approximately 730 newborn infants suffocate to death before they reach 27 days old for no apparent reason and termed SIDS/SUIDS incidents, and that is what we think we know of. Humans are obligate nose breathers and may require 6-8 weeks to develop the physical ability to breathe through their mouth. Some health experts believe an infant may require as much as 12 weeks developing this ability.

Choanal atresia is a life threatening birth defect in which an infant's nasal passage fails to develop normally during pregnancy. Health professionals believe this occurs during the 6-8th week of pregnancy. One side (unilateral) or both sides (bilateral) of their nasal passage can be blocked by bone or membrane matter, thus preventing an infant from breathing normally. Common belief among health experts is that while bilateral choanal atresia, (both sides blocked) is life threatening requiring immediate intervention, unilateral CA can be delayed to school age or adulthood; nothing can be further from the truth.



¹Unilateral choanal atresia does not require surgical treatment as urgently as the bilateral case and can be postponed until school-age when the anatomy of the region is more similar to that in adults.

However, according to Children's Choanal Atresia Foundation's response from mothers having a child born with CA find that the vast majority, (over 90%) are not diagnosed at birth. According to CDC data ²) *The incidence of this malformation is between 1:5000(730) and 1:8000 (457) live births. It is more often unilateral than bilateral (60% vs. 40%) and occurs more frequently in females than in males (ratio 2:1).*

Yet the data is incredibly inaccurate, as the attached data sheet reflects an unimaginable distortion of data. Of the 50 US states, which 34% do not provide any data on CA whatsoever, California has the most births 420,031 annually, yet has only 8 incidents of choanal atresia. Florida has 216,236 births and 166 incidents of CA, while New York with 210,359 births has 231 incidents, and Texas, 373,340 births has 212 incidents of choanal atresia incidents; these are 2021 data figures published by the CDC. Furthermore, California which leads the nation in number of births annually list 8 incidences yet Arkansas, which ranks 40th in number of births, has 12 incidences. A deeper analysis of the data reveals that the 1/5000-1/8000 occurrence data is completely inaccurate. Based on the commonly accepted incidents rate by the CDC of 1/7000 births, there is a **327% disconnect** in the figures between CDC estimates and actual recorded incidents, *see attached chart*. In most cases that number is more than triple the CDC data. There may be a far greater number of infants who are not diagnosed at birth who may not be part of this statistic. [3]*For many defects it has been determined that the extent of underreporting is quite substantial.* When a child is older, the medical treatment to repair or treat choanal atresia is often referred to as rhinoplasty, sinusitis, or treatments other than choanal atresia including allergies.

[3] *It should be borne in mind that data presented in this report do not reflect the entire incidence of congenital defects. The completeness of reporting of a malformation depends primarily on the recognizability of the defect within the short period after birth before the filing of the birth certificate. However, even where the presence of a malformation is noted on the hospital record, there may be a failure to transfer the information to the birth certificate.*

The NIH/NICH and CDC's apparent disinterest in choanal atresia is reflected in the data, or lack thereof, as represented in published CDC research data. Truly NIH/NICH comments "Choanal atresia is a rare birth defect that does not warrant research funding" and 'The present method of treatment is both cheap and expedient' are reflected in this lack of accurate data and research. Both comments come from top medical experts at the NIH/NICH and CDC and are further reflective of the indifference and lack of support by a broken government's laissez-faire approach to treatment, care, and trauma newborn babies and mothers must endure. Without doubt the data reflects an unconceivable lack of judgment and accuracy on the part of health professionals and government agencies. As an Industrial Engineer with over 30 years experience in data analysis I am profoundly disheartened by the disconnect between the data, poor judgments of health care professionals, and the lack of research that can lead to improved diagnoses, treatment, and care for these babies.

Choanal atresia is a birth defect that impairs a newborn baby's ability to breathe normally at birth. The data on choanal atresia is so corrupted and inaccurate it bears no reflection of the true nature of this birth defect and the sociological, emotional, and psychological impact it has on newborn infants, their deaths due to a failure to properly diagnose, or the trauma newborn babies must endure, and the horror and frustration of mothers responsible for the care these neonate infants require more than a casual after thought. This indifference begins with, governing agencies, politicians, and health care professional's that impact the entire healthcare industry and its response to a birth defect that goes largely ignored and undiagnosed at birth, and is responsible for the deaths of untold newborn babies subsequently termed SIDS incidents. In light of the newly discovered Nasal Cycle and its impact on neonate breathing rhythms coupled with failure to properly timely diagnose unilateral choanal atresia, the health profession should be deeply concerned and cautious regarding the decisions to delay intervention until these babies reach school age or adulthood. This decision puts these infants in grave danger especially with unilateral CA; it is definitely not the "insignificant" birth defect so commonly referred to. We believe strongly this may be a significant contributor to infant deaths prior to 27 days of age and SIDS/SUIDS incidents.

Additionally, there are no studies on the impact oxygen deprivation may have on the emotional, psychological, and educational development of these children. Consider the impact of this profound failure to diagnose or or the perceived lack of concern; Unilateral Choanal Atresia is in fact far more

dangerous and life threatening than Bilateral CA, Bilateral CA demands immediate attention and intervention as a newborn infant is obviously unable to breathe. Unilateral CA on the other hand, is not readily apparent. A visual check of a newborn infants nasal passage is not part of the APGAR Protocol. We fear the vast majority of these infants go undiagnosed and the data supports our concerns. Combine this lack of immediate diagnoses and treatment and the innate breathing cycle and breathing patterns of humans, these infants are in serious danger of a catastrophic breathing failure resulting in death due to suffocation; all because health experts decided unilateral CA is non-emergency.

Respectfully,

James Loomis, Founder, CEO, Children's Choanal Atresia Foundation a 501(C3) nonprofit founded in 1989.

A handwritten signature in black ink, appearing to read "James Loomis". The signature is fluid and cursive, with a large initial "J" and "L".

<https://www.babynose.org/>

References:

[1][2]<https://www.ncbi.nlm.nih.gov/>; *National Library of Medicine, Treasure Island (FL): StatPearls Publishing*; 2022 Jan-.; Choanal Atresia, *Claudio Andaloro; Ignazio La Mantia.*

[3]https://www.cdc.gov/nchs/data/series/sr_21/sr21_031.pdf; National Vital Statistics System, Congenital Anomalies and Birth Injuries Among Live Births.

[4]<https://www.ccentsinus.com/blog-nasal-cycle.html> What is the Nasal Cycle? *Posted November 24th, 2020*

* <https://pubmed.ncbi.nlm.nih.gov/?term=choanal+atresia>; STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY, Updated August 2013, Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention; <https://pubmed.ncbi.nlm.nih.gov/?term=choanal+atresia>

Coanal Atresia by State vs Births (2021)
 Division of Vital Statistics, National Center for Health Statistics

State	# Births	CA Incidents	CDC Avg 1/7,000	
		Actuals	Births	
Alabama	58,032.00	0	0.0	States with highest births (4)
Alaska	9,258.00	0	0.0	States that fall within the 1/7000 range (9)
Arizona	77,891.00	0	0.0	States with 100,000+ births (7)
Arkansas	35,902.00	7	5.1	34% of states have No/Data
California	420,031.00	8	60.0	*Data includes DC
Colorado	62,900.00	70	9.0	
Connecticut	35,647.00	0	0.0	
Delaware	10,477.00	2	1.5	
*District of Columbia	8,644.00	0	0.0	
Florida	216,236.00	166	30.9	
Georgia	123,939.00	20	17.7	
Hawaii	15,565.00	0	0.0	
Idaho	22,426.00	0	0.0	
Illinois	132,117.00	87	18.9	
Indiana	79,760.00	62	11.4	
Iowa	36,783.00	38	5.3	
Kansas	34,690.00	10	5.3	
Kentucky	52,144.00	29	7.4	
Louisiana	57,218.00	22	8.2	
Maine	12,003.00	0	0.0	
Maryland	68,262.00	7	9.8	
Massachusetts	69,142.00	30	9.9	
Michigan	104,830.00	92	15.0	
Minnesota	64,398.00	13	9.2	
Mississippi	35,146.00	4	5.0	
Missouri	69,375.00	0	0.0	
Montana	11,222.00	0	0.0	
Nebraska	24,555.00	26	3.5	
Nevada	33,655.00	22	4.8	
New Hampshire	12,615.00	2	1.8	
New Jersey	101,457.00	82	14.5	
New Mexico	20,910.00	0	0.0	
New York	210,359.00	231	30.1	
North Carolina	119,792.00	87	17.1	
North Dakota	10,108.00	3	1.4	
Ohio	129,717.00	0	0.0	
Oklahoma	48,350.00	40	6.9	
Oregon	40,868.00	0	0.0	
Pennsylvania	132,401.00	0	0.0	
Rhode Island	10,458.00	3	1.5	
South Carolina	57,129.00	22	8.2	
South Dakota	11,368.00	0	0.0	
Tennessee	81,675.00	71	11.7	
Texas	373,340.00	212	53.3	
Utah	46,701.00	20	6.7	
Vermont	5,383.00	0	0.0	
Virginia	95,944.00	81	13.7	
Washington	83,838.00	0	0.0	
West Virginia	17,080.00	5	2.4	
Wisconsin	61,719.00	39	8.8	
Wyoming	6,230.00	0	0.0	
Total	3,659,690.00	1613	415.9	

What the CDC data says they should have based on 1/7000 births

Actual CA incidents

There is a 327% difference between CDC estimates and actual CA incidents

327% difference

N/D = No Data