

He was the first to notice. Or, more likely, the first to say it. “There’s something up with her ears.” ...Within minutes, he [my husband] was in the corner on his iPhone, diagnosing our daughter before anyone else had the chance to. Microtia, he said. Atresia. It meant nothing to me. But then, I *looked*. There wasn’t just something wrong with her ears—she barely *had* ears. More alarmingly, there were no ear canals. Just two little peanuts on either side of a perfect little head, so perfect on its face that it seemed to mock the malformations on its sides.

<http://ivyleagueinsecurities.com/2013/05/my-sisters-birth-story/#sthash.s3P3j1AE.dpuf>



The FAQs of Microtia/Atresia for Parents and Professionals

Meredith Berger, MS Ed.

2025 EHDI Conference Pittsburgh, PA 3/10/2025



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- Parent of 2
 - 1 with microtia/atresia (*disclosure-uses Cochlear Bahas)



References





DOES YOUR CHILD HAVE MICROTIA/ATRESIA?

PLEASE JOIN OUR STUDY!

Researchers want to learn more about parents' beliefs and their opinions of their own skill, known as parental self-efficacy (PSE), in taking care of their child's microtia/atresia related needs and the relationship between PSE, children's development and intervention services.

What is involved?

- ✓ Complete 1 demographic survey
- ✓ Complete 1 survey about PSE, your child's development, and your child's intervention services.

Eligibility

- ☐ Parent is at least 18 years old
- ☐ Child has microtia/atresia and is aged 36 months or younger
- ☐ Live in the United States
- ☐ Can complete 2 online surveys in either English or Spanish
- ☐ Have 1 hour of time to complete 2 surveys



For questions contact:
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Register



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¿SU HIJO TIENE MICROTIA/ATRESIA?

¡POR FAVOR ÚNETE A NUESTRO ESTUDIO!

Los investigadores quieren aprender más sobre las creencias y opiniones que tienen los padres de familia sobre sus habilidades cubriendo y cuidando las necesidades de su hijo/a con microtia/atresia auricular, el desarrollo infantil y los servicios de intervención temprana.

¿En qué consiste?

- ✓ Completar 1 encuesta sobre antecedentes médicos y familiares
- ✓ Completar 1 encuesta sobre PSE, el desarrollo de su hijo, y los servicios de intervención.

Elegibilidad

- ☐ La madre o el padre tiene 18 años o más
- ☐ El niño tiene microtia y tiene 36 meses o menos
- ☐ Vive en los Estados Unidos
- ☐ Puede completar encuestas en línea en inglés o español
- ☐ Dispone de entre 1 hora de tiempo para completar 2 encuestas



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https://tccolumbia.qualtrics.com/jfe/form/SV_dmU7yWaEpV8hMHQ?Q_Language=ES



Learning Outcomes

Participants will....

- 1...generate questions parents of children with microtia/atresia have after their child's birth.
- 2...identify answers to common questions asked by parents of children with microtia/atresia.
- 3...will discuss and develop strategies for supporting parents of children with microtia/atresia.



Agenda

1

- Context and initial questions

2

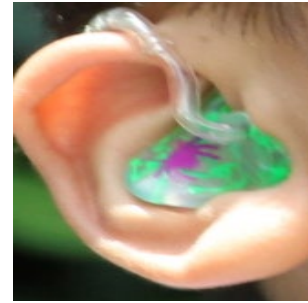
- Research, guidelines and resources to address questions and provide information

3

- Strategies and supports for families



1:3:6



④ May

①

③

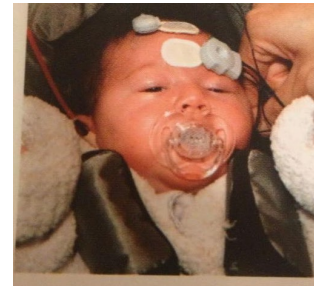
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March 10

April

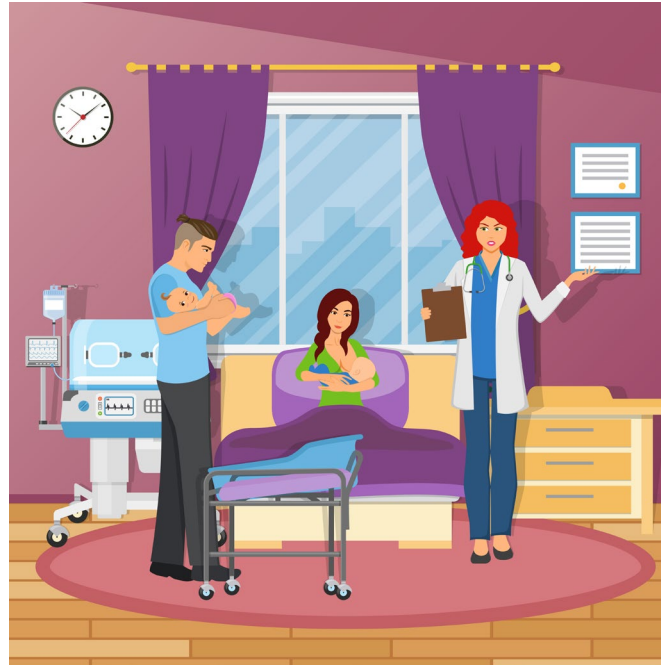
June

September





Pikisuperstar@freepik



<https://www.freepik.com/auth or/macrovectorofficial>

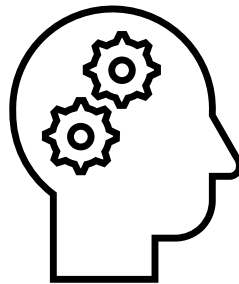




Guilt/Blame

Who?
What?
Where?
When?
Why?
How?

Fear of
future

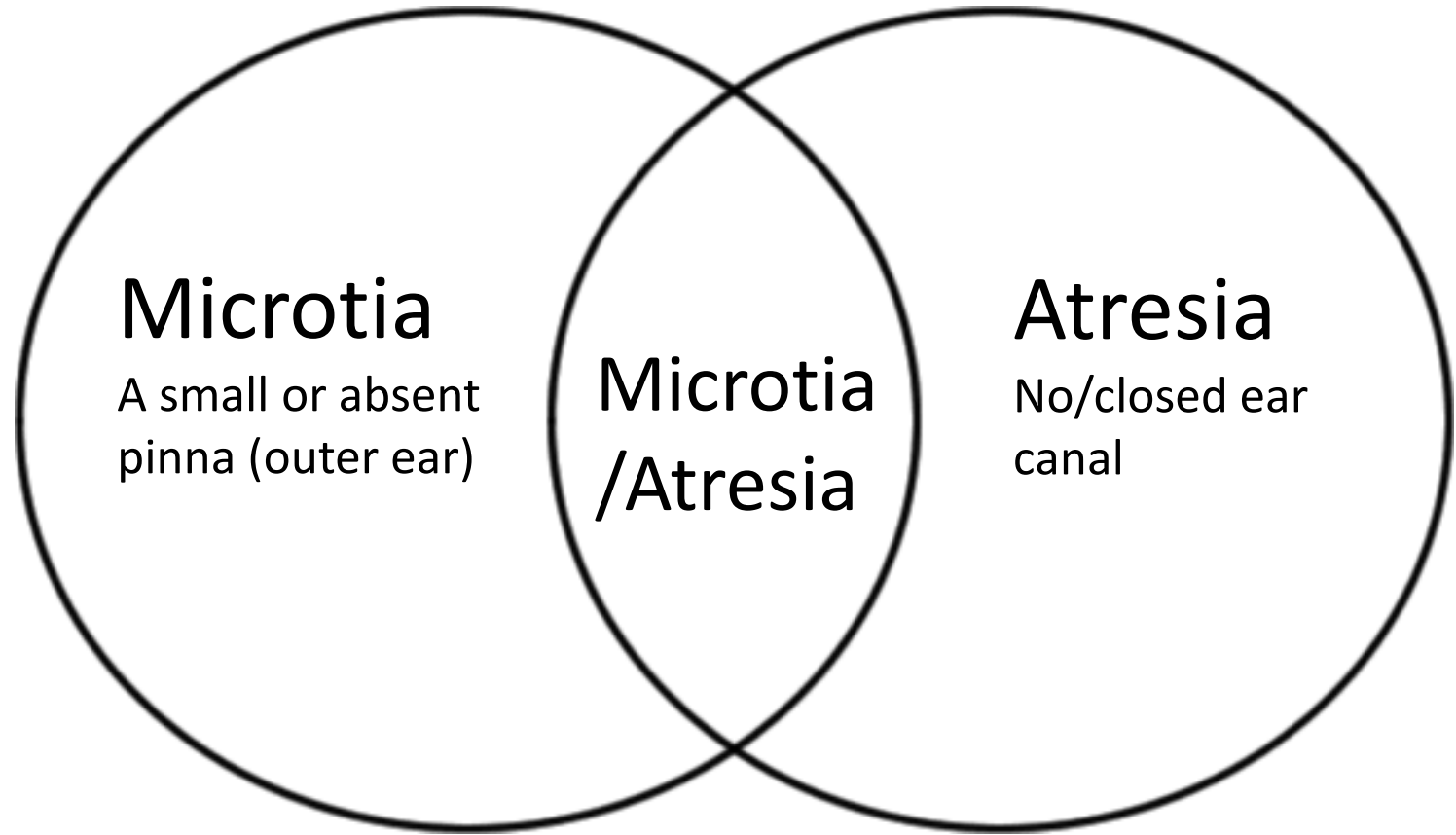




What is it?

WHAT IS MICROTIA /ATRESIA?

Microtia/Atresia
Aural Atresia
Unilateral Atresia
Unilateral Conductive Hearing Loss
Permanent Unilateral CHL
Atresia
Anotia



Types



Grade I Microtia



Grade II Microtia



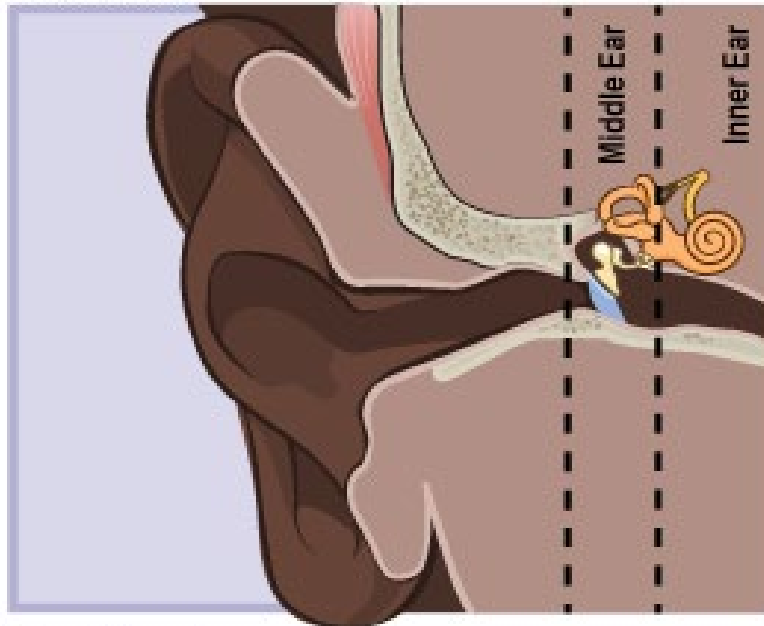
Grade III Microtia



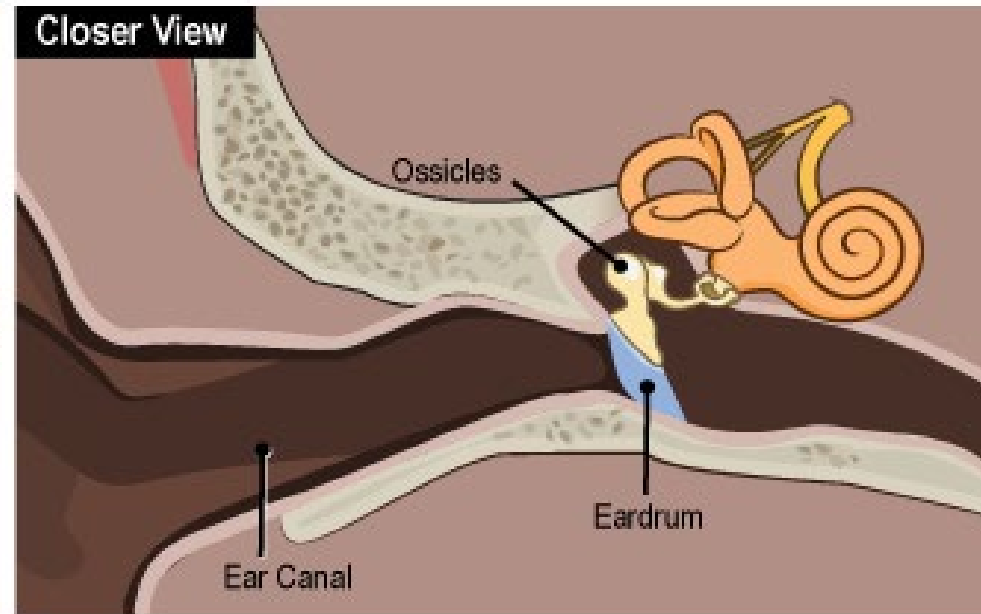
Grade IV Microtia



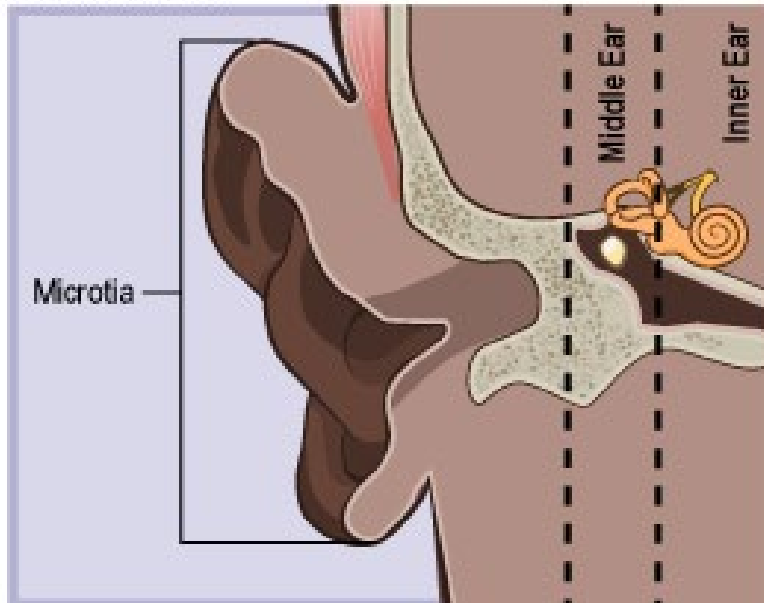
Normal Ear



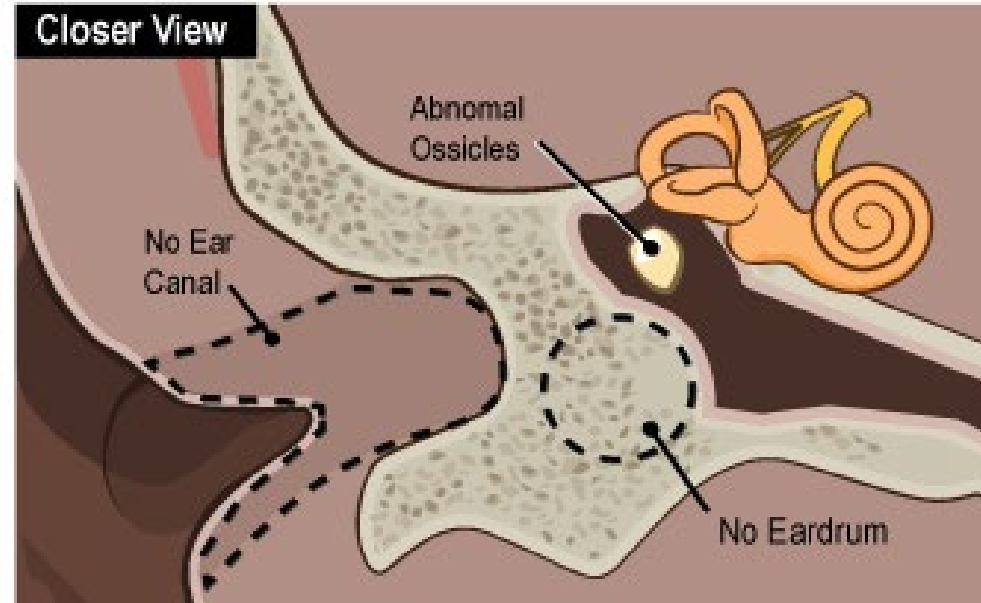
Closer View



Aural Atresia



Closer View



Quick Facts

- Develops early in 1st trimester
- First and second branchial arches (around the 4-8th week of gestation) (García-Castro et al., 2022)
- More common in males
- Unilateral (>90%), right ear (60%)
- Syndrome related -<20%
- Conductive hearing loss >90% (Wang et al., 2023)






What did I do wrong?
Why didn't they see it?
How did this happen?

NOTHING



Genetics?

- Limited but growing research
 - Most research on syndrome-related or adults
 - 40 suspected genes-
 - HOXA2, MUC6 and GSC
- (Govindan et al., 2025; Putri et al., 2022)



Henrietta B. and Frederick H. Bugher
Professor of Cardiovascular Genetics

Jonathan Seidman, PhD

Mapping genetic loci associated with microtia using Kids First DRC whole genome sequence data

<https://youtu.be/kzV4wmpOmes?si=d861PW6ejg3LGePl&t=1028>



Prenatal testing

- Fetal ultrasound-high false positive rate for isolated m/a; more reliable with complex or multiple craniofacial anomalies (Lamanna et al., 2023; Lunardhi et al., 2023; Qiu et al., 2023)
- MRI-higher accuracy, more likely if other anomalies exist (Zhang et al., 2023)



Correlation \neq Causation

- *Difficult pregnancy*
 - History-miscarriage (5.5x higher ≥ 3)
 - Progesterone use
 - Bleeding/cramping during pregnancy
- *Exposure to chemicals*
 - Example: pesticides, formaldehyde
- *Prematurity* (Shehan et al., 2022)
 - Race- Asian+M/A > prematurity
- *Non-singleton birth*
- *Anemia in 1st trimester*
- *Type 1 or 2 diabetes before pregnancy*
- *Altitude* (>2500-3500m) (Noroña et al., 2024)
- *Racial/ethnic background*

During pregnancy:

- binge drinking
- ≥ 300 mg of caffeine daily
- ≥ 5 cigarettes daily

Estimates of 1/10,000 - 5/10,000

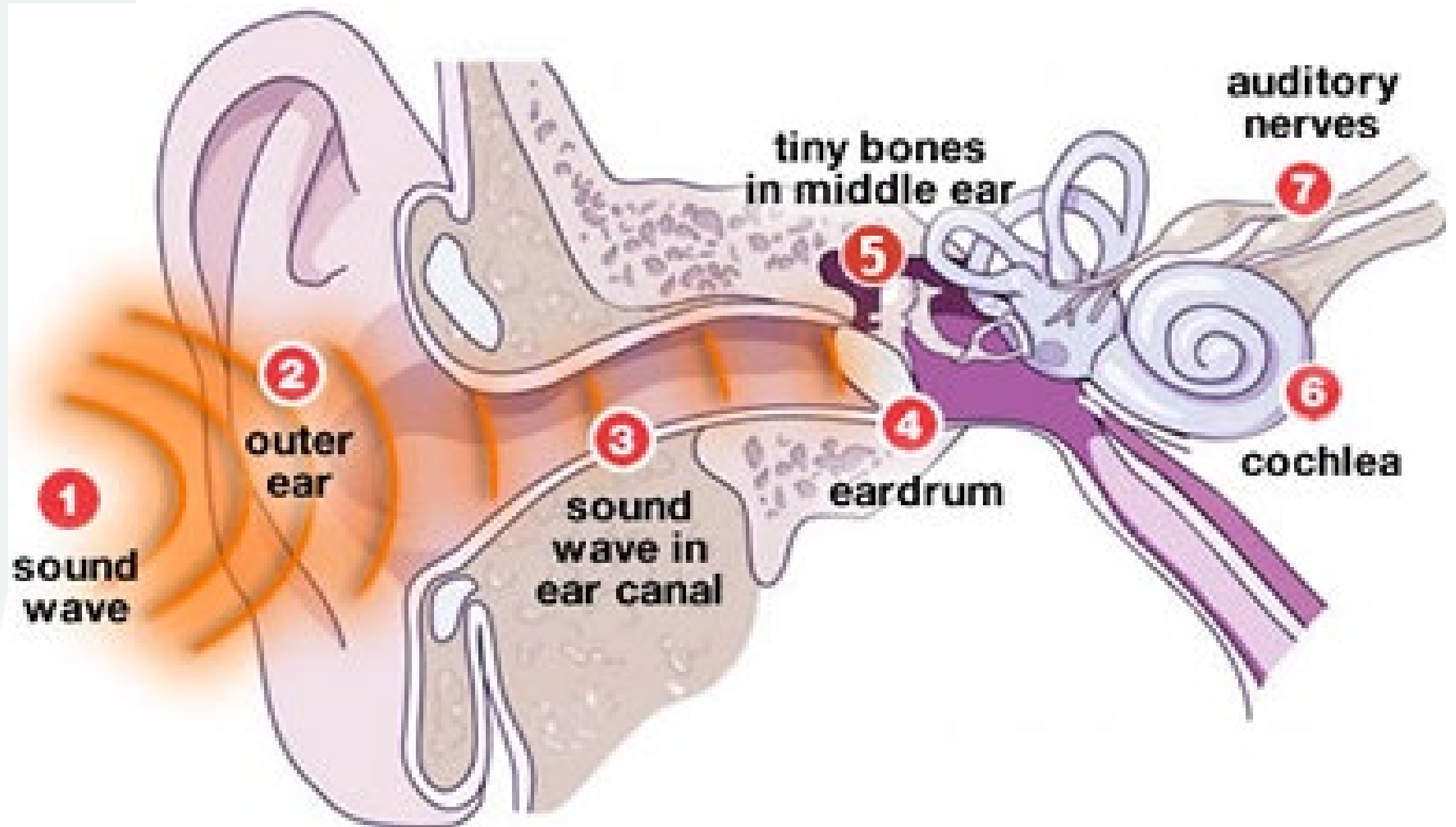
(Center for Disease Control and
Prevention, 2018)

- Hispanic/Latino-7x higher
Ecuador 17/10,000 (Noroña et
al., 2024)
- Asians-3x higher
- African/descent .86/10,000
(Shaw et al., 2004)

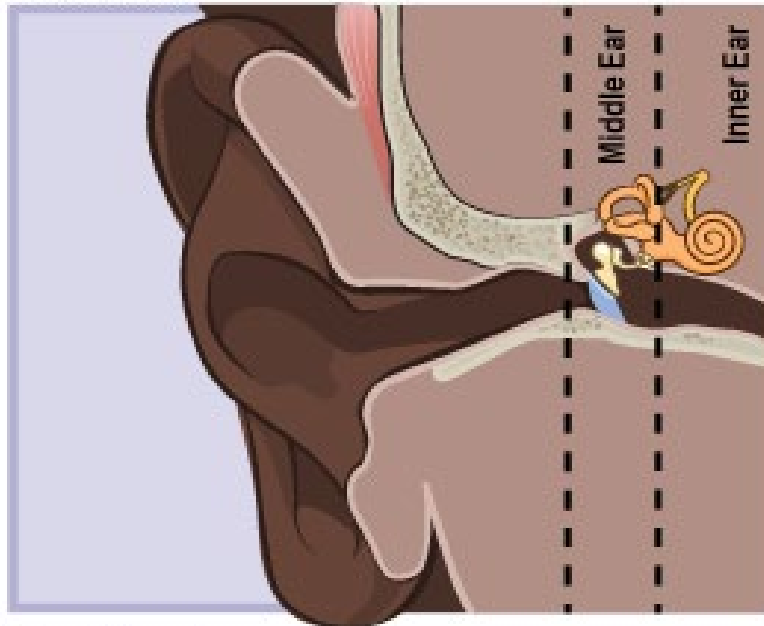




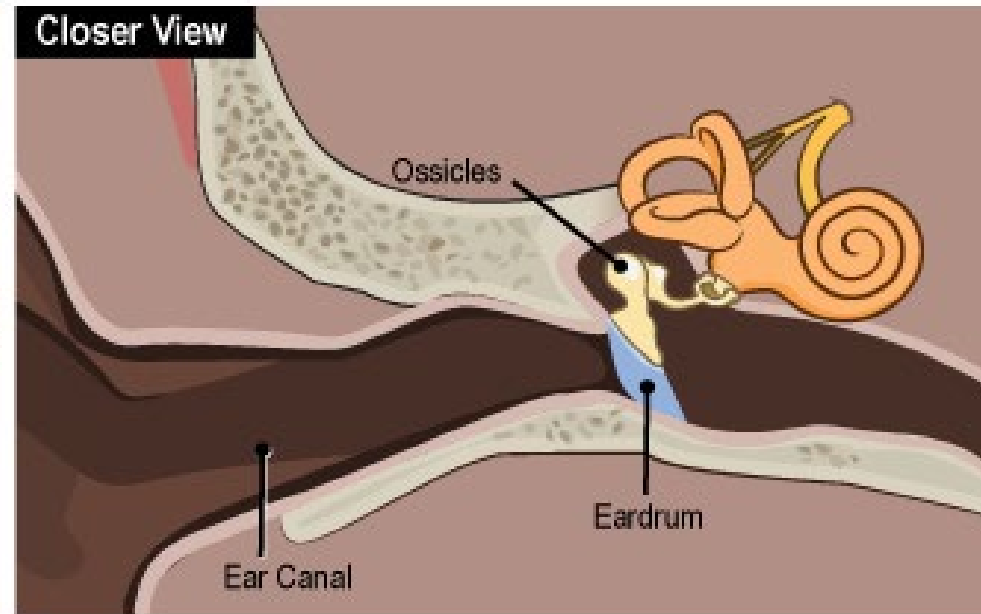
How does my baby hear?



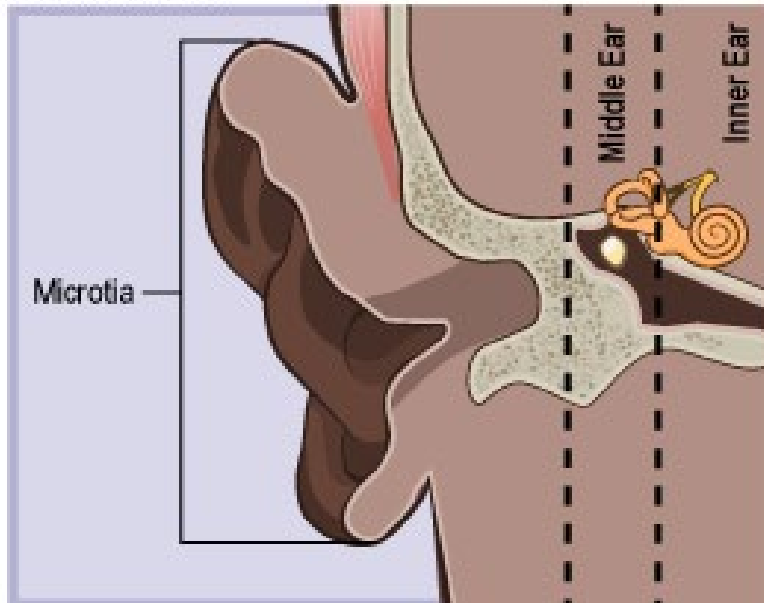
Normal Ear



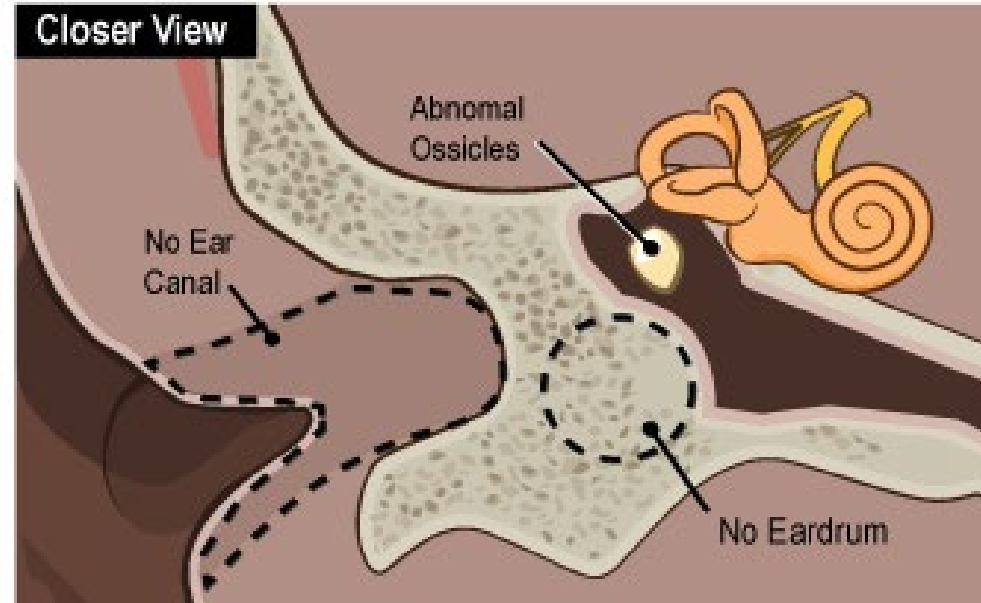
Closer View



Aural Atresia



Closer View

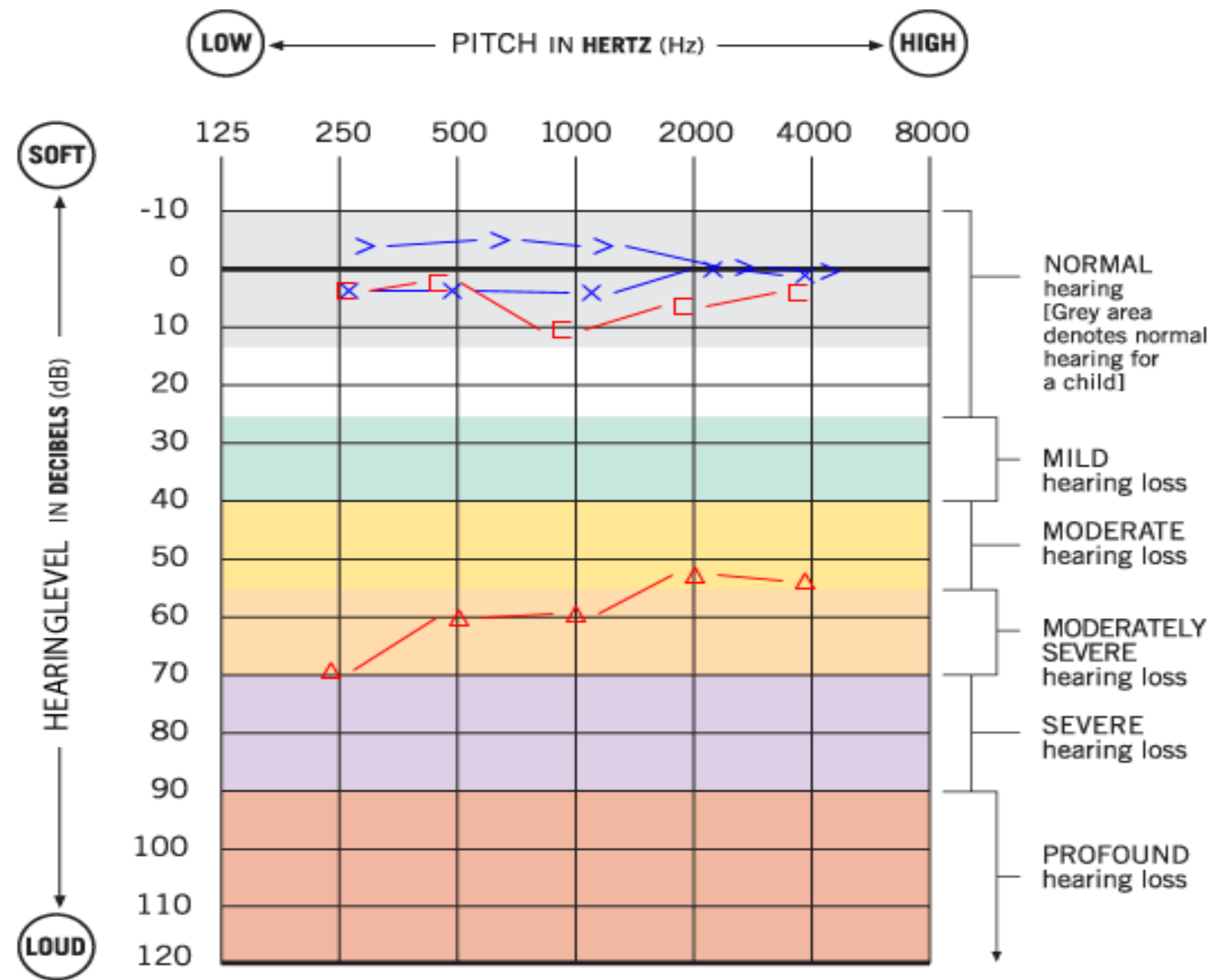


Maximum Conductive Loss- Air/bone gap= cochlear function

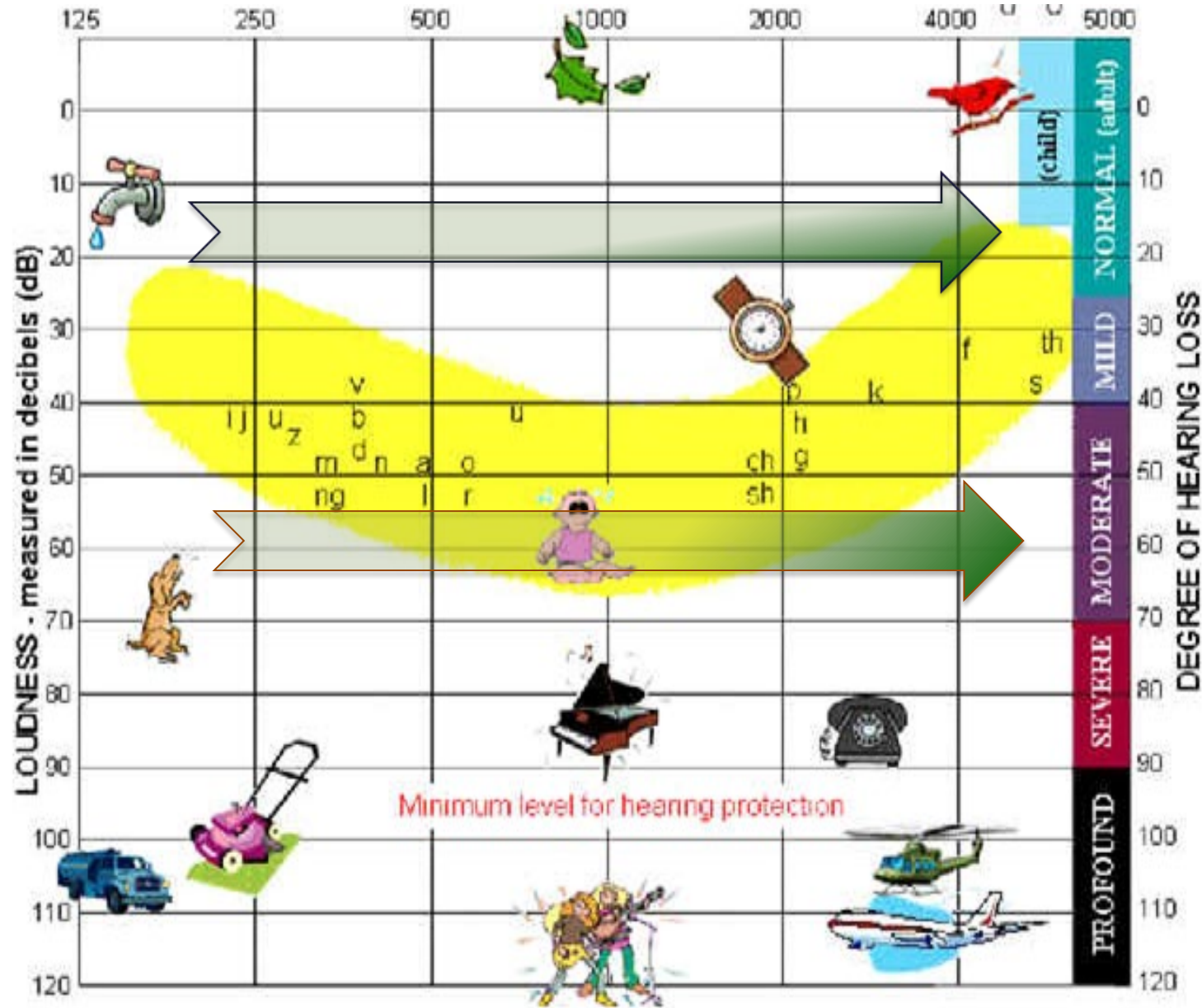
“Normal cochlea function”

≠

“normal hearing”



Lost in the Gap



Bone
Responses



Air
Responses





What other medical needs should we look for?
Who are the specialists we should see?

Kidneys

- 3-25% of children-renal abnormalities
- Rx: ultrasound screening- all

Urinary Function

(Sun et al., 2023)

- Girls-MA-most likely
- Rx: early urinalysis-all > id functional issues;  structure

Heart

(Guo et al., 2021)

- ~8%-at least 1 congenital heart defect
- Rx: Doppler echocardiogram at birth, screened pre-surgery

Vertebrae

(Alexander et al., 2023)

- ~10% (w/imaging) had abnormalities
- Rx: rib graft surgery complications-chest wall deformity

Soft palate

van Hövell tot Westerflier et al., 2019

- Isolated & Syndromic-high rates of uvular deviation and VPI
- Rx: in- depth evaluation of soft palate movement and VPI

Ears

- tubes, other ear; cholesteatoma-stenosis
- RX: Otologist, or experienced ENT





❖ Craniofacial team

- Ears: ENT/Otologist
- Hearing: Audiologist
- Kidneys:
- Heart:
- Urinary Function:
- Craniofacial:





What's next?

And when?



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JCIH 2019 Recommendations

(Joint Committee on Infant Hearing, 2019)

Newborn Hearing Screening



Infants with congenital aural atresia in one or both ears or with visible pinna/ear canal deformity such as stenosis or severe malformation **should not be screened in either ear** but should be **referred for diagnostic audiologic evaluation immediately** upon discharge. *The diagnostic audiologic evaluation can also be accomplished while the infant is in the NICU or other inpatient hospital unit.*

Early Intervention Services

The purpose of early intervention is to achieve optimal child and family outcomes. Hence, the audiologist must make the referral for Part C Early Intervention (IDEA, 2004) services as quickly as possible following confirmation that a child is deaf or hard of hearing. Federal regulations require that this referral be made within seven working days of diagnosis (IDEA, 2004). **In cases of congenital aural atresia, the referral can and should be made by the birth hospital.**



Options. (Reinisch and Lewin, 2009),

Age	Audiological	Ear Canal	Ear Reconstruction	Therapy and support
Birth-3 yrs 	<u>Diagnostic Testing</u> <ul style="list-style-type: none"> • ABR, behavioral <u>Amplification</u> <ul style="list-style-type: none"> • Non-surgical (Baha, Ponto, Adhear) 			Early Intervention <ul style="list-style-type: none"> • Language Development • Parent Supports 
>3 yrs			Medpor/Supor Reconstruction	Preschool IEP Special Education Programs and Services
>5 yrs	Bone Conduction Devices (BCD) <ul style="list-style-type: none"> • Surgically implanted 	Atresioplasty Canalplasty		K-12th grade IEP <ul style="list-style-type: none"> • Services, Programs, FM/DM, Accommodations
≥ 7 yrs			Rib Cartilage Graft	K-12th grade IEP <ul style="list-style-type: none"> • Services, Programs, FM/DM, Accommodations

Clinical consensus document for fitting non-surgical transcutaneous bone conduction hearing devices to children. (Bagatto et al., 2021)

Purpose: Address the assessment, selection, and fitting for non-surgical bone conduction devices for children under age 5

- Goal is to fit within 1 month of diagnosis
- Children as young as 2 months
- Bilateral m/a=bilateral BCDs (sequential, based on age)



Why is amplification needed?

- Increase use of amplification if parents receive early and clear information (Kazemir et al., 2022)
- Children (who use BCD) with language delays were fit later than children without delays (Florentine et al., 2022)
- If early fit, age-appropriate language and academics. (Hyland et al., 2020)
- Children with microtia/atresia are hard of hearing and.... (Cañete et al., 2021)
 - Sound localization
 - Focused auditory attention in school situations
 - Perception of the direction, distance, and movement of sound.
 - More effort and inability to ignore sounds were reported as major difficulties.





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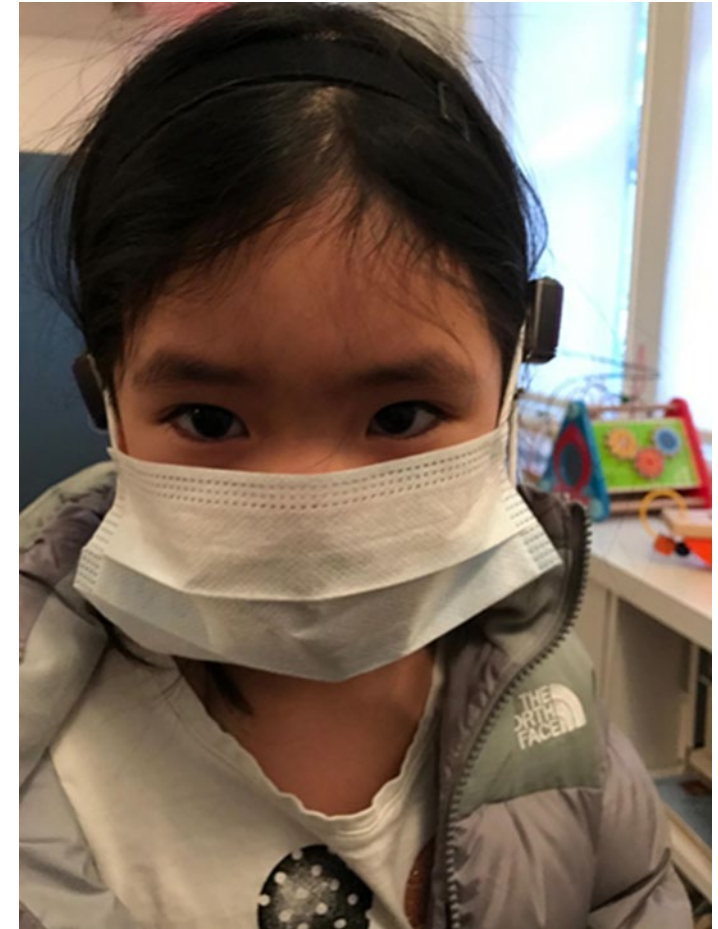
SCHOOLS FOR HEARING & SPEECH

How will this impact the future?

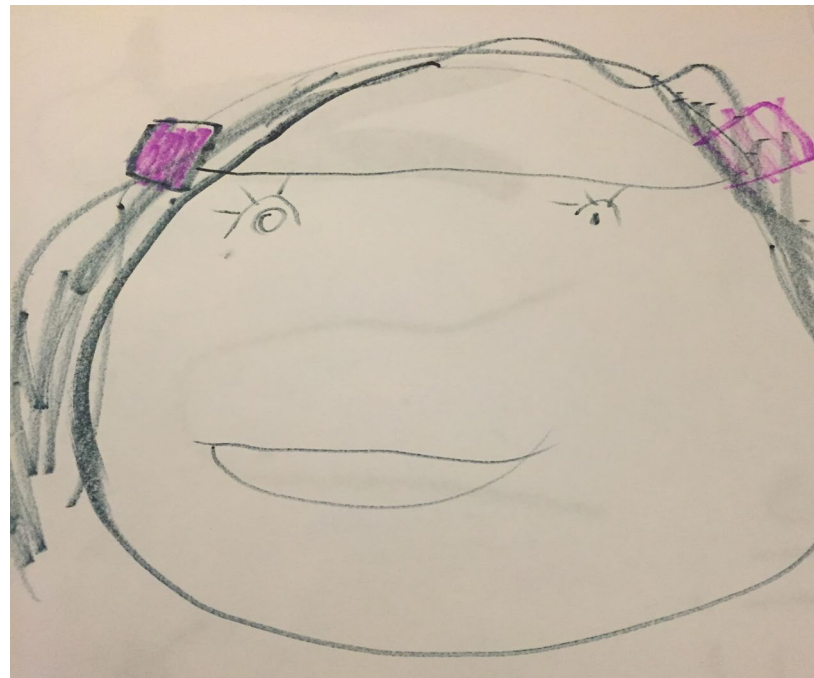
Bullying

(Johns et al., 2021)

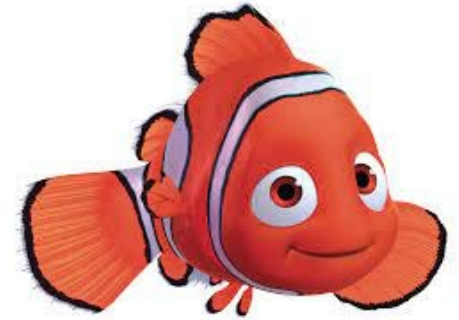
- 169 children, average 10 years old
- 40% parents reported their child being teased
- 49% reported “some of the time”
- 39% reported “almost never”
- Teasing started around age 5 (US), age 7 (South America)
- 85% teasing occurred at school
- No correlation with amplification, HL, IEP services



Paradigm Shift



MICROTIA AND ATRESIA AWARENESS



Resources

The Ear Community Facebook, website, Ear Community picnics

Facebook groups Microtia Parents & others specific to countries/regions

myFace myFace.org

Little Baby Face Foundation <https://www.littlebabyface.org/>

Hearing First Sophie's Story <https://www.hearingfirst.org/celebrate-lsl/lsl-life/sophie>

Give an Ear Foundation (South Africa based/Africa focused)

<https://giveanearfoundation.org>

Microtia UK <http://microtiauk.org/>

Microtia Atresia Australia <https://microtiaatresia.com.au/>



Ear Community Picnics

<https://earcommunity.org/2025-picnics-and-events/>



6/14/25
Idaho Falls, Idaho



7/12/25
Long Island, New York



6/21/25
Richmond, Virginia



7/19/25
Atlanta, Georgia



6/28/25
Wilton Manors, Florida

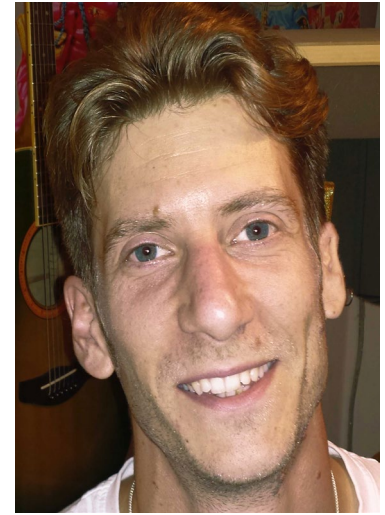


7/26/25
Nashville, Tennessee



7/19/25
Oakville, Canada





Jono Lancaster

Camilla Gilbert

Gideon Glick

Nick John Wilson

Cynthia Murphy

Paul Stanley

Salia Baligh

Joshua Cheptegei

Advocate

love me, love my face

Motivational speaker

Actor

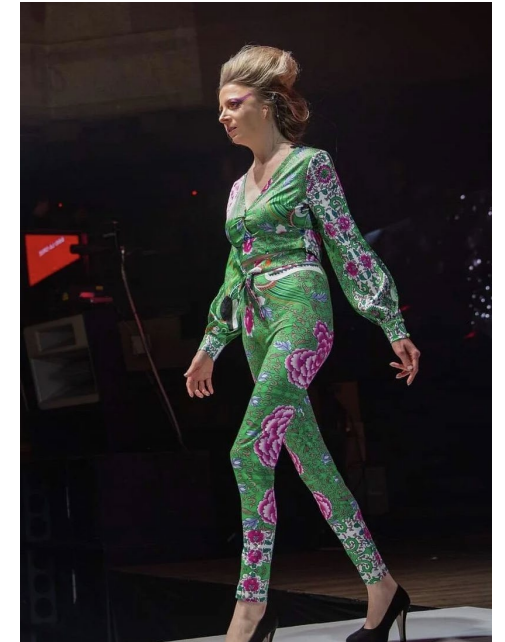
Singer/song writer

Model/Advocate

KISS drummer

2023 Rose Parade Princess

2024 10



Books

Jojo's Tiny Ears Stefania Munzi-Logus
Hi, I'm Me & Hi, I'm Me in Kindergarten
Kelly Vurinaris
Ricky the Rock That Couldn't Roll
Tess, the Tin that wanted to Rock Mr. Jay
Rebekah's Superpower Emma Bilyk
Wonderfully Different, Wonderfully Me
Becky Zingale
Asha's Little Ear Becky Zingale
The Adventures of Billie BAHA and Her
Superhero Friends Jessica Jordan-Hogan
Sophie's Little Adventure Dawn Calvert
Little Ear, Big Hear Jacob Rosales
Jaycee's Little Ear Devan Lusk





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References



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