

# Research and Practice

## Supporting Professionals, Families, and Children with Microtia/Atresia

2026 Early Hearing Detection and Intervention Conference

Jacksonville, FL

Meredith Berger, MEd



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[mberger@clarkeschools.org](mailto:mberger@clarkeschools.org)  
[mb4374@columbia.edu](mailto:mb4374@columbia.edu)

- Director-Clarke School/New York
- PhD candidate Teachers College, Columbia University

## Disclosures

### **Financial disclosure:**

Clarke Schools for Hearing and Speech-paid employee

### **Non-financial disclosure**

NYS EHDI Advisory Board  
Cochlear Americas-spouse/child  
both use Cochlear devices





# Learning Outcomes

## Participants will.....

- analyze current research, policies, and clinical practices related to children with microtia and atresia.
- develop evidence-based guidance to support the diverse needs of children with conductive hearing loss and their families.
- identify effective communication and family-centered practices that empower parents and enhance developmental outcomes for children with microtia and atresia.



# Agenda

1

Review current research, policies, and practices

2

Consider guidance to support children and families

3

Discuss practices that empower parents and enhance developmental outcomes for children with microtia/atresia





"Research is something that everyone can do, and everyone ought to do. It is simply collecting information and thinking systematically about it."

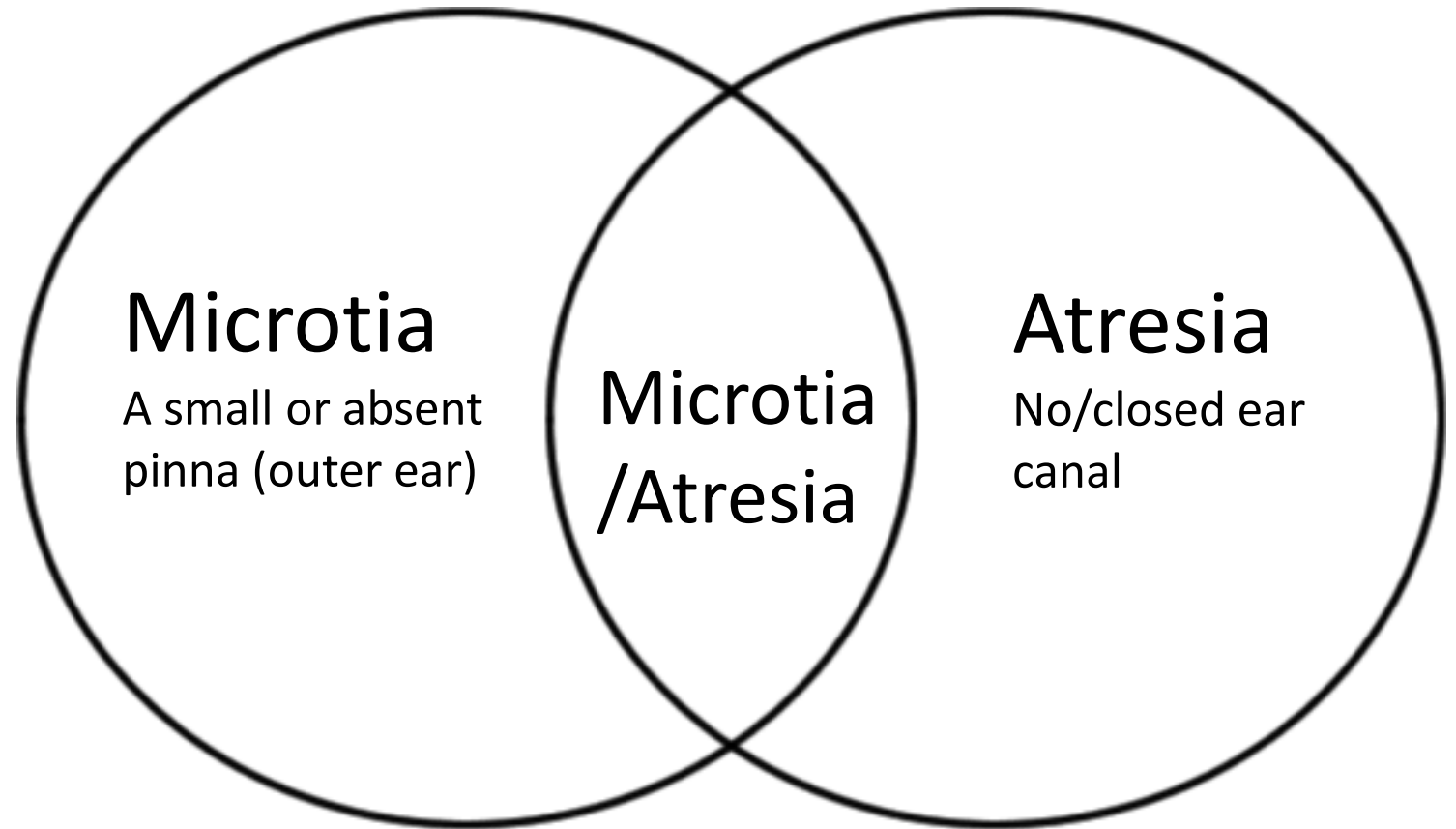
Raewyn Connell





What is microtia/atresia?

# ***WHAT IS MICROTIA/ATRESIA?***



**Microtia/Atresia**

**Aural Atresia**

**Unilateral Atresia**

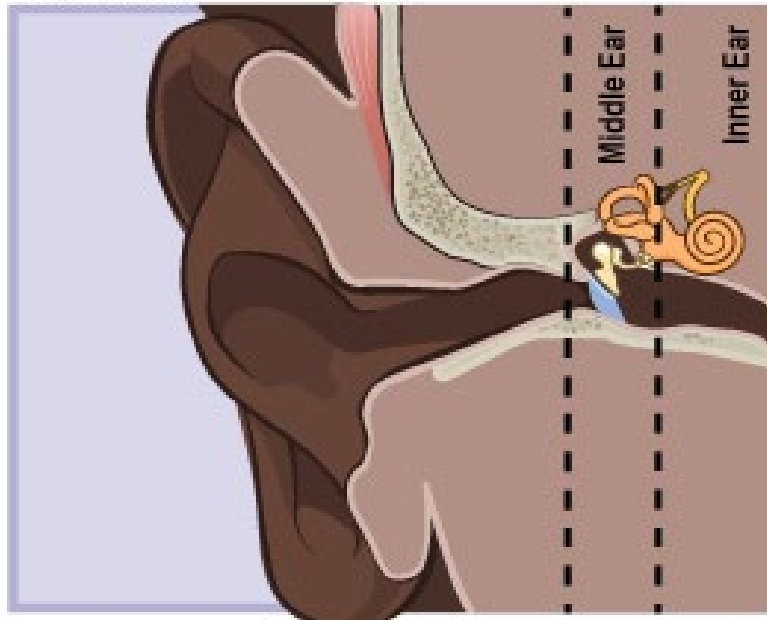
**Unilateral Conductive Hearing Loss**

**Permanent Unilateral CHL**

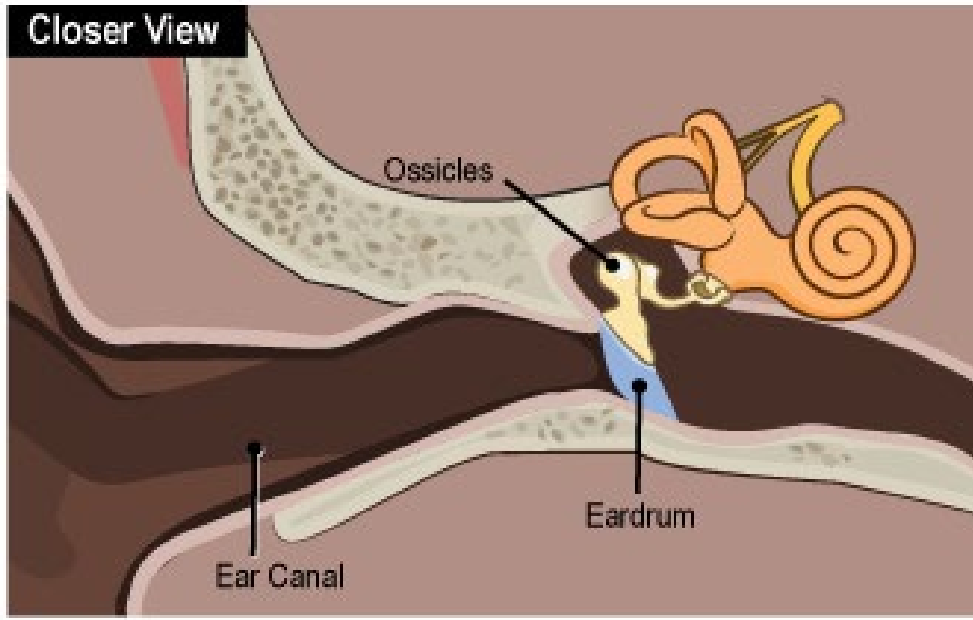
**Atresia**

**Anotia**

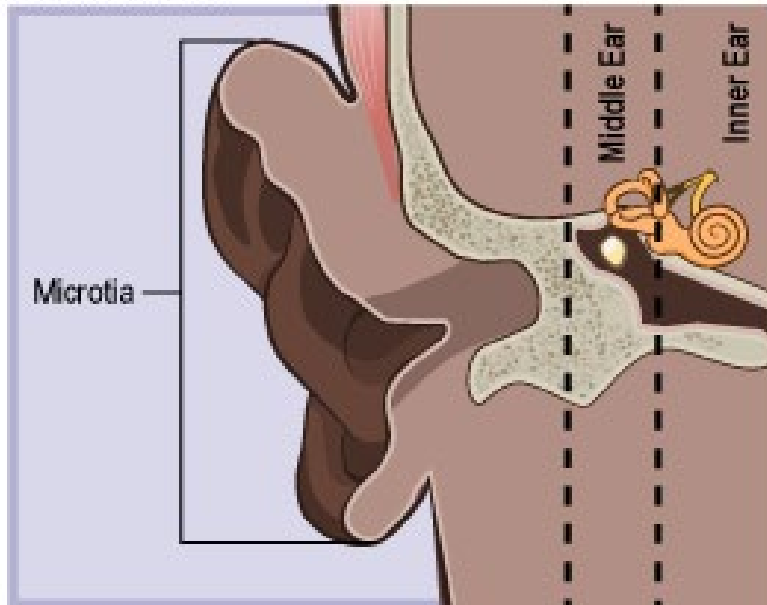
### Normal Ear



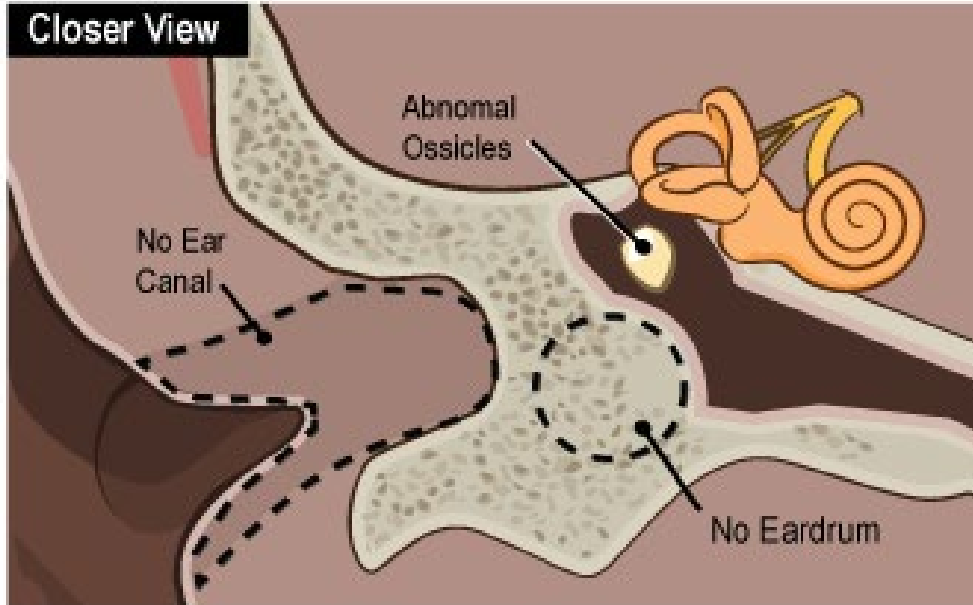
### Closer View



### Aural Atresia



### Closer View



# Types (pinna)



**Grade I Microtia**



**Grade II Microtia**



**Grade III Microtia**



**Grade IV Microtia**



# Quick Facts

- Develops early in 1<sup>st</sup> 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)
- Hispanic, Asian, Pacific Islander, Native American-higher; Chile and Ecuador- 3-8x > (Luquetti et al., 2012)





# Policies and Practices



# 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

*In cases of congenital aural atresia, the referral can and should be made by the birth hospital.*



# EI Regulations

Each state's definition of an infant or toddler with a disability **must** include an infant or toddler with....A diagnosed physical or mental condition with a high probability of resulting in developmental delay. ([34 CFR § 303.21](#))

## Florida

- Auditory Neuropathy
- **Aural Atresia (bilateral or unilateral)**
- Sensorineural hearing loss in excess of 25 dB HL

## New York

- a hearing impairment (a diagnosed hearing loss that cannot be corrected with treatment or surgery).
- *Cost of HAs/BCDs/HAT covered*

## Pennsylvania

State policy does not go beyond federal regulatory language.



# Current Research



**CLARKE**

SCHOOLS FOR HEARING & SPEECH

# What's new with amplification and device use?

## 1. (Abell et al., 2026)

- Multidisciplinary care (MDC)
- 319 of 507 (63 %) children MDC.
- MDC-higher rates of BCD use (82.1 % vs. 53.7 %)
- Lower age at fitting (0.8 years vs. 2.5 years,  $p = 0.011$ ).

## 2. (Scollie et al., 2025)

- Update to (Bagatto et al., 2021) on best practices for nonsurgical BCD fitting
- Addresses the revised Desired Sensation Level prescriptive algorithm for BCD with Verafit and skull simulator



# What's new in outcomes?

**(Kim et al., 2026)** N=67 BCD=19 children (28.4%) Ages 4yrs-10 yrs

Articulation: significantly delayed,

Rec. Vocabulary: WNL Expressive Vocab: below average

**(Picou et al., 2025)** N= 417 60 (13%) with microtia/atresia

-increased risk of needing specialized support, such as speech therapy



# What's new on social media?

1. **Websites** (Báez Berríos et al., 2025) (Boroumand et al., 2025)
  - Reading level exceed AMA/NIH guidelines; quality-low or too complex.
  - 99 sites- 27.3% included representation other than White.
2. **AI** (Dadi et al., 2026)
  - None met both standards.
  - Google Gemini-best quality; DeepSeek-best readability
3. **Tiktok** (Fu et al., 2025)
  - Inconsistent quality and reliability. understandable and actionable info
4. **Facebook** (Umbaugh et al., 2020)
  - Most posts are parents seeking guidance (43%; 9 themes)



# What's new with parents/caregivers?

- **(Stock et al., 2025)**
  - Healthcare providers should use neutral and accessible language
  - Decision making practices should be shared
  - Expand discussion topics beyond reconstruction and surgery
- **(Yang & Yang, 2024)**
  - Caregivers face substantial financial, psychological, and social challenges
  - Need for targeted supports and interventions.
- **(Rahman et al., 2024)**
  - Spanish speaking parents.
  - Needs: interpreters, Spanish materials, addressing care barriers, accounting for the role of extended family.





# Guidance for Parents



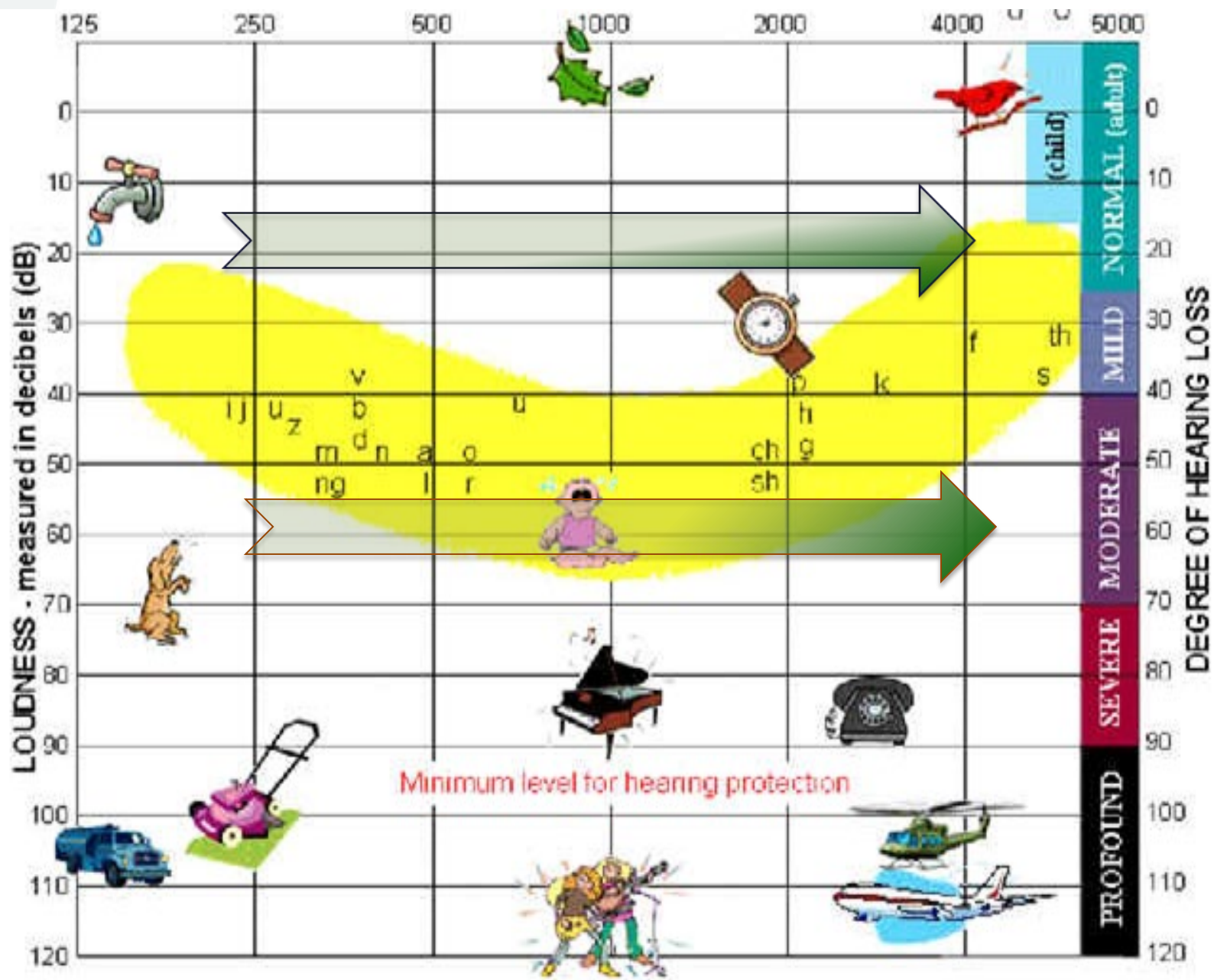
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# Why is amplification needed?

- 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)
  - Focused auditory attention in school situations
  - Perception of the direction, distance, and movement of sound.
  - More effort & inability to ignore sounds were major difficulties.





Bone Responses



Air Responses




## Kidneys

(Kini et al., 2020) (Koenig et al., 2018)

- 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:

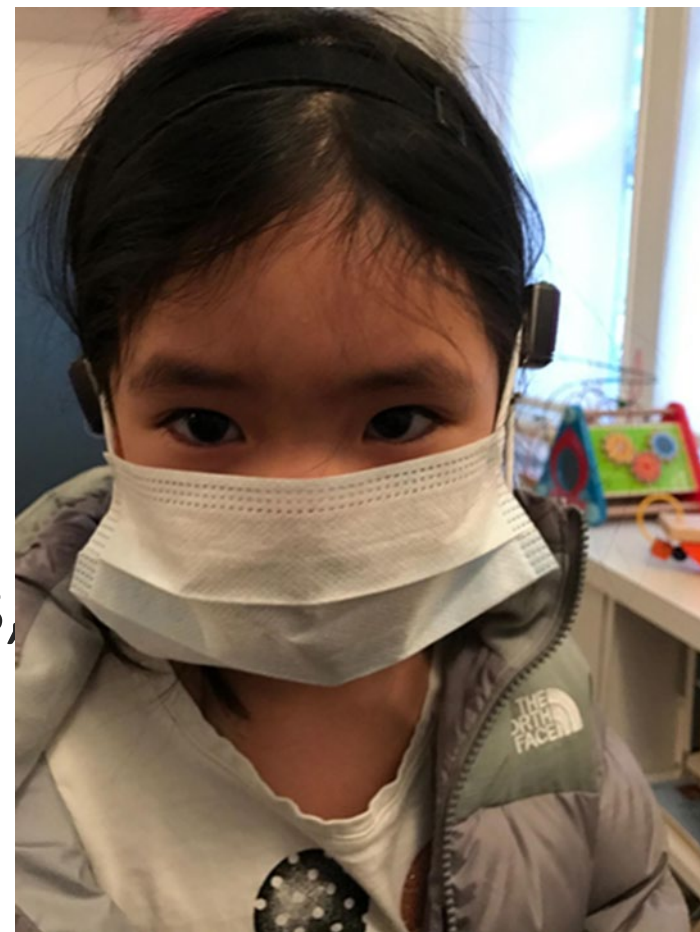




# Empowering Parents

# Information & Acknowledgement

- “Nothing”
- It is hard.
- Bullying is a real concern (Johns et al., 2021)
  - But not inevitable!
  - Acknowledge contradictory advice
  - Family and strangers' questions, comments, and stares



# What helps?

- Connect with other parents
- Therapists with M/A experience
- Awareness of unique situations
  - Car seats, highchairs, strollers
  - Hats and helmets
  - Thermometers
  - Masks



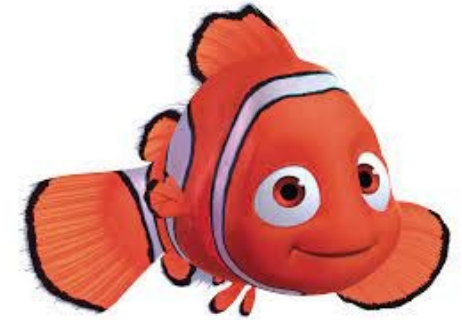
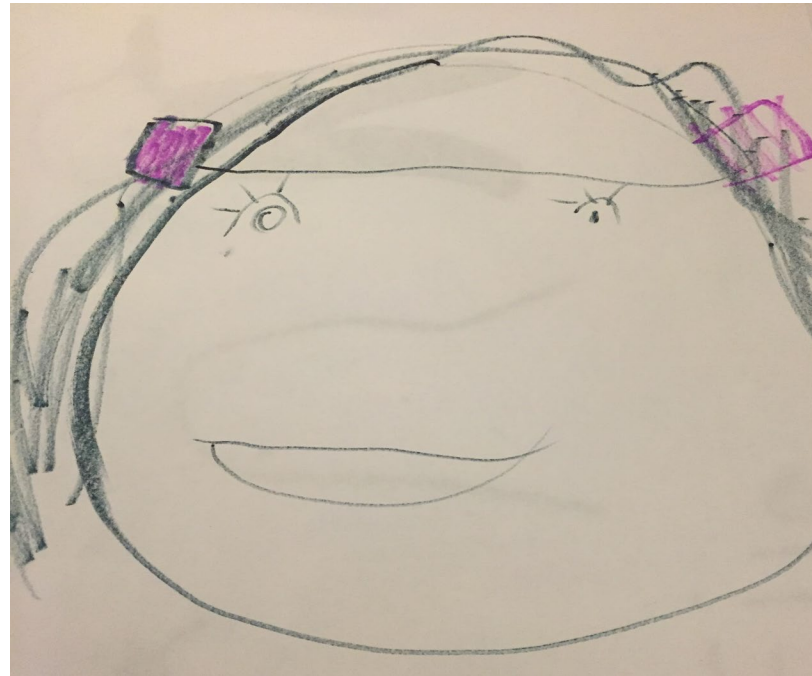
Banz (on amazon)



Raskullz ★★★★★ 468  
Raskullz Kitty Cat Toddler 3+ and Child 5+ Helmets



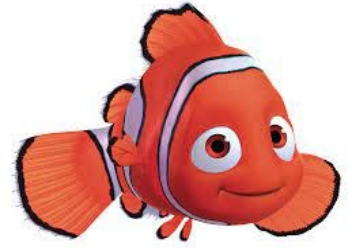
# Paradigm Shift



MICROTIA AND ATRESIA AWARENESS



# Paradigm Shift



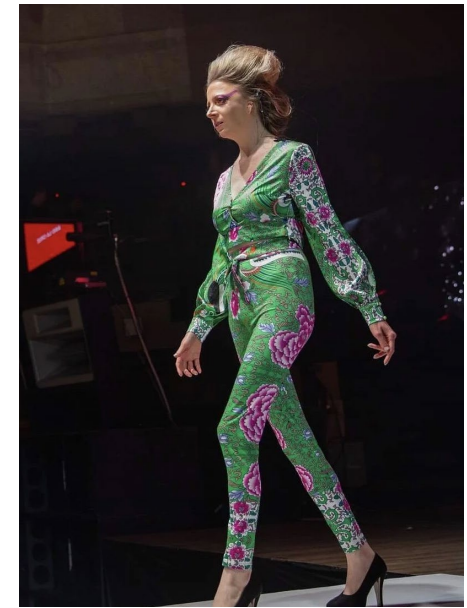


# Microtia in the Wild



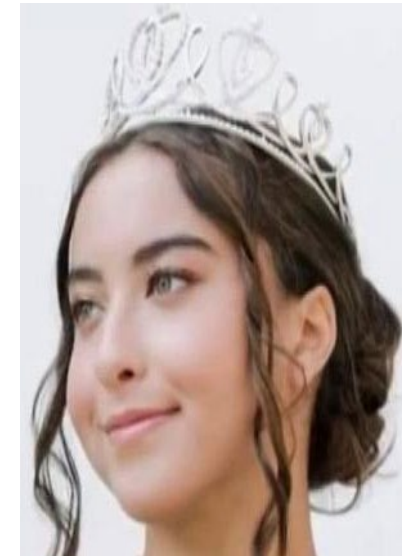
**CLARKE**

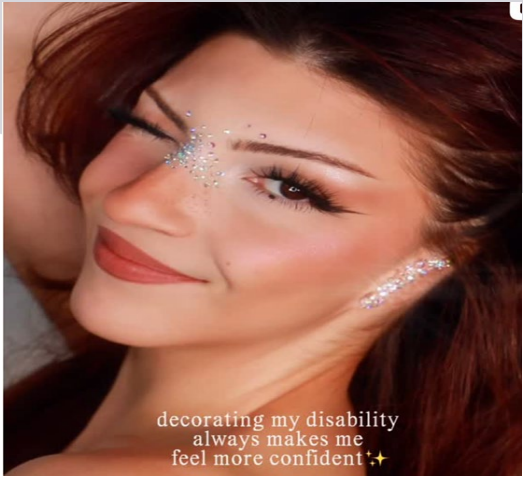
SCHOOLS FOR HEARING & SPEECH



Camilla Gilbert  
 Gideon Glick  
 Nick John Wilson  
 Cynthia Murphy  
 Paul Stanley  
 Salia Baligh

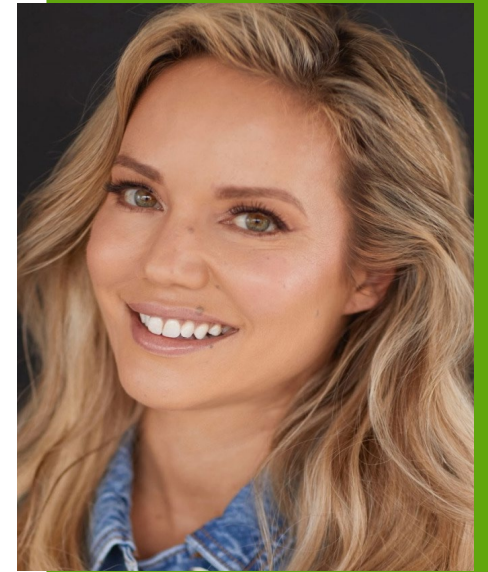
Motivational speaker  
 Actor  
 Singer/song writer  
 Model/Advocate  
 KISS drummer  
 2023 Rose Parade Princess





Hayley Hessian  
<https://www.instagram.com/hayleyelizabethmua/>

Sasha Gardner, model,  
podcaster  
<http://www.youtube.com/@sashasayspodcast>  
<https://www.instagram.com/sashasayspodcast/>



Joshua Cheptegei  
2024 10K Olympic Medalist



Jono Lancaster  
Advocate  
*love me, love my face*

Rachel Raak  
SolaceShields



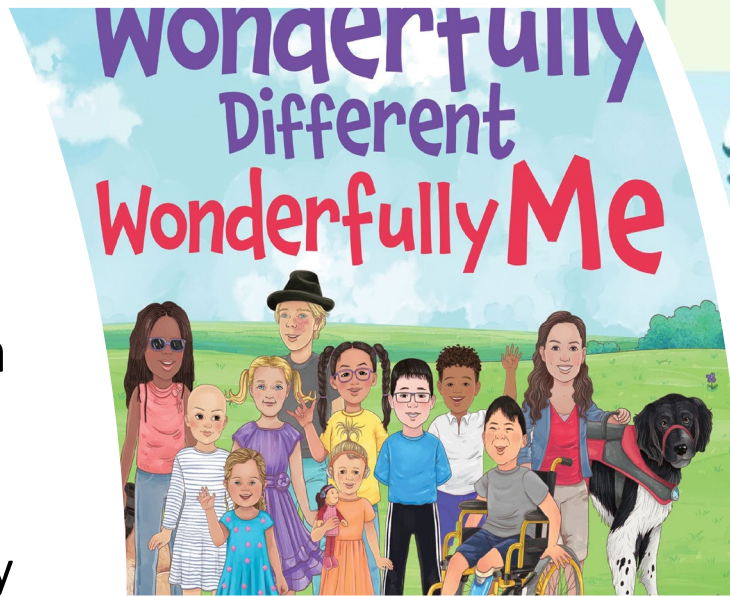
# Priscila Soares

- BCD user (not m/a)
- Artist/illustrator
- Myluckyears (Instagram)
- Myluckyears.com



# 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



# 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-1st/1st-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/>





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