

**“I remember my husband bringing him over. But he was whispering to the nurse: oh
“We’re not really equipped for him. Go figure!”
“The doctor just said you’re not equipped for hearing-impaired kids. And
th knew something was up. You know, but I didn’t know what it was.”
th that possibility was in the air. I don’t know what she’s like, I guess
that was it. there was this cloudy, scary, sickening what-she-says-we’re
we’re not really equipped for him.” Go figure!”**

Parental Experiences Following the Birth of a Child with Microtia/Atresia

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Disclosures

Non-Financial

- Children's Hearing Institute-Medical and Educational Advisory Board
- NYS EHDI Advisory Committee
- Parent of a child with microtia/atresia, uses Cochlear bahas

Financial

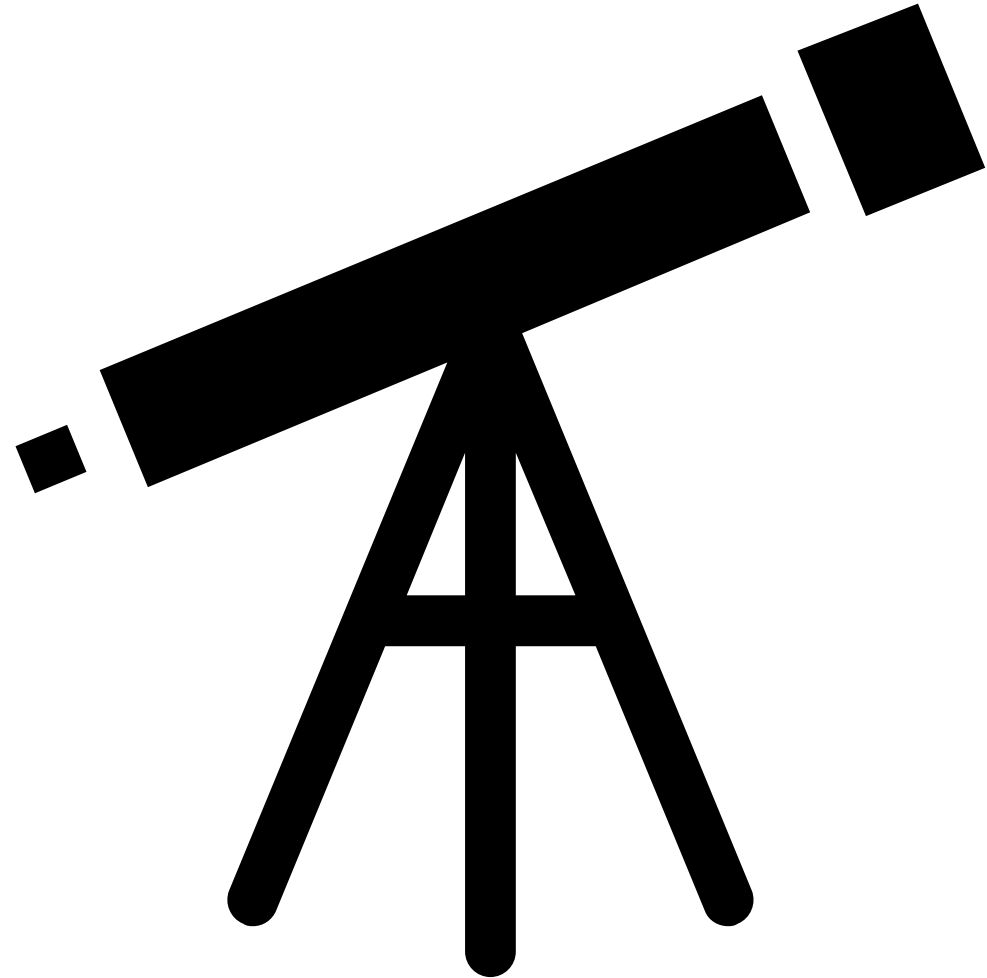
- Employed by Clarke Schools for Hearing and Speech

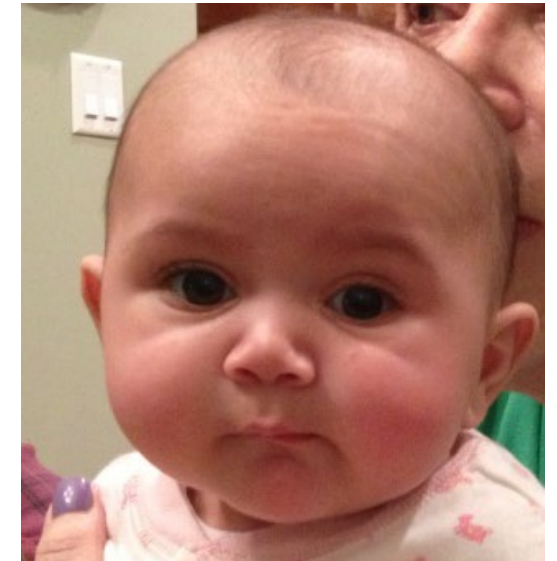
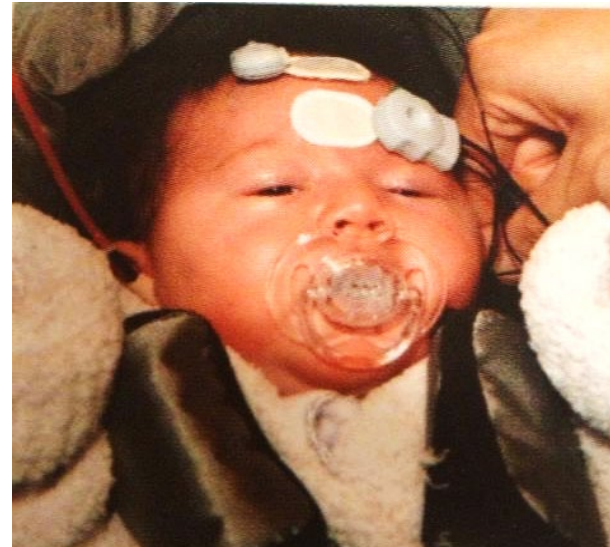
Learning Outcomes

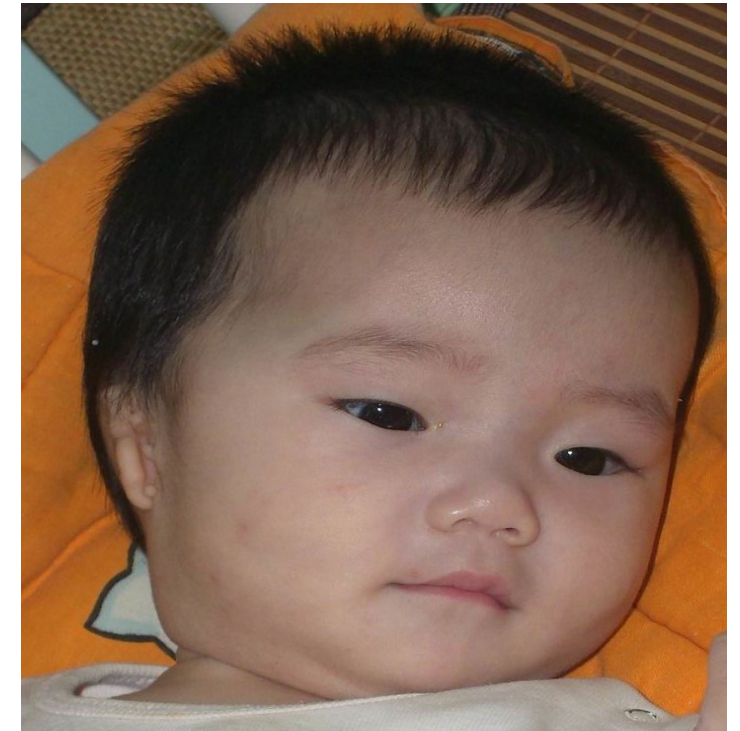
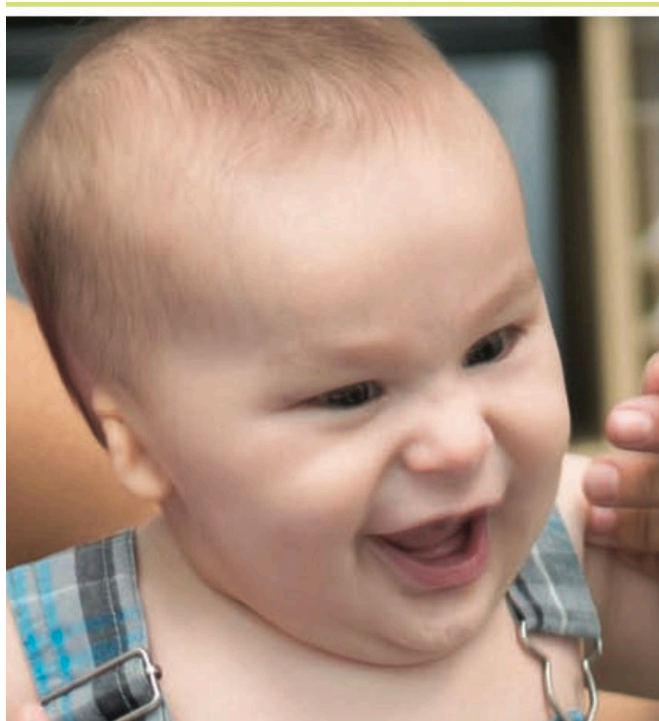
- Participants will be able to summarize JCIH guidelines and current research on parent perspectives and experiences following the birth of a child with microtia/atresia
- Participants will be able to describe themes across parent experiences following the birth of a child with microtia/atresia
- Participants will be able to identify strategies for supporting families of children with microtia atresia that align with the goals of JCIH and EHDI.

What are the experiences, perspectives, challenges, and needs of parents following the birth of a child with microtia/atresia (aural atresia)?

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2019 JCIH Guidelines

(The Joint Committee on Infant Hearing, 2019)

1:3:6

- 1 All infants-hearing screening no later than one month of age
- 3 Diagnostic audiologic evaluation to confirm the infant's hearing status no later than 3 mo
- 6 Family centered EI services services should begin ASAP and no later than 6 months of age

And:

Immediate referral to Early Intervention.

Immediate access to high-quality, well-fitted, and optimized hearing aid technology.

If the family chooses, fitting of hearing aid amplification **no later than four months of age**

JCIH Recommendations-Microtia/Atresia

Timing of 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.

Referral to 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.**

Children with mild bilateral and unilateral hearing loss: Parents' reflections on experiences and outcomes.

Fitzpatrick, E., Grandpierre, V., Durieux-Smith, A., Gaboury, I., Coyle, D., Na, E., & Sallam, N. (2016). Children With Mild Bilateral and Unilateral Hearing Loss: Parents' Reflections on Experiences and Outcomes. *The Journal of Deaf Studies and Deaf Education*, 21(1), 34–43. <https://doi.org/10.1093/deafed/env047>

20 parents of children mild bilateral or unilateral

- 4 children had conductive loss.
- Diagnosis process was hard and filled with uncertainty
- Importance of the hearing loss was minimized by professionals
- Uncertainty about need for amplification

Parental preferences for the first consultation for microtia.

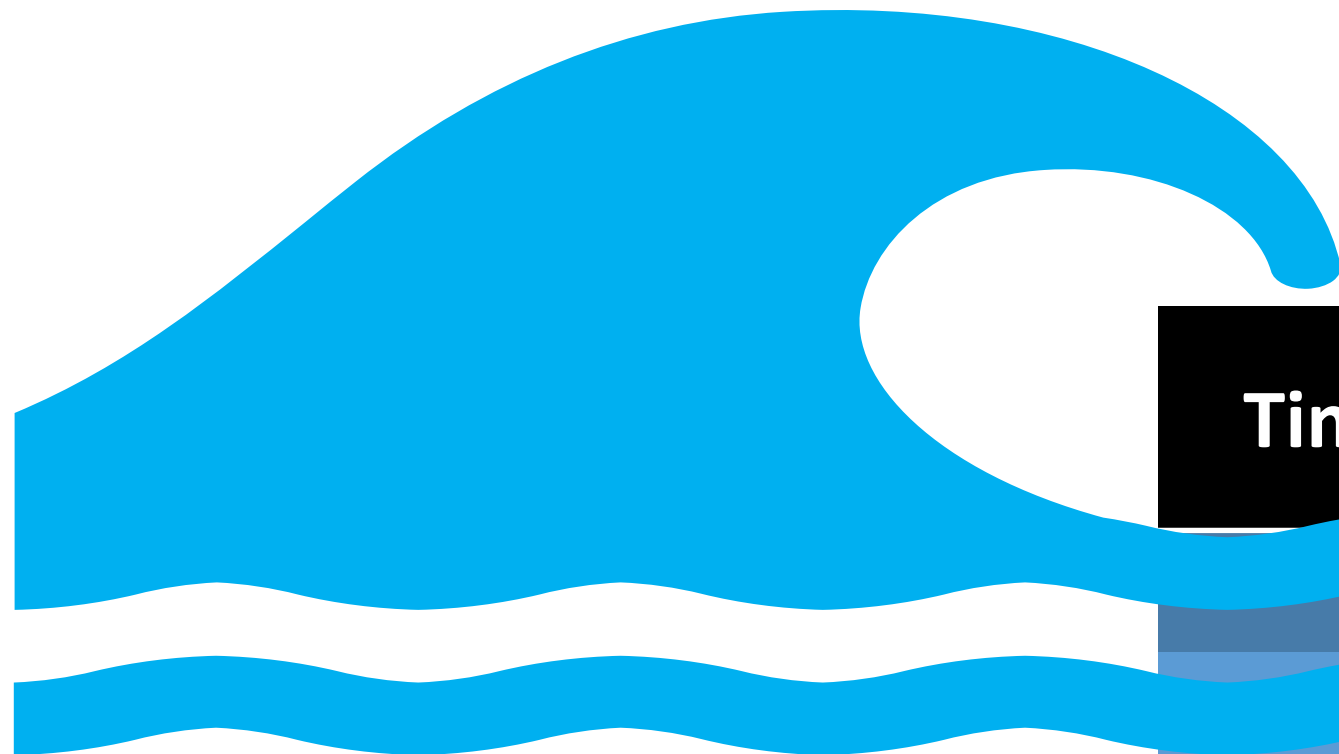
Westerflier, C. V. V. H., Stegeman, I., Muradin, M. S., Smit, A. L., & Breugem, C. C. (2018). Parental preferences for the first consultation for microtia. *International journal of pediatric otorhinolaryngology*, 106, 10-15.

- 87 parents
- Survey regarding initial information presented to parents after their child's birth
- 26% received no information after birth
- 60% of parents describe the initial informing consult as “terrible” or “bad”
- 1 parent (.01%) described initial consult as “excellent”

Microtia: epidemiology and genetics

Luquetti, D. V., Heike, C. L., Hing, A. V., Cunningham, M. L., & Cox, T. C. (2012). Microtia: epidemiology and genetics. *American Journal of Medical Genetics Part A*, 158(1), 124-139.

- 0.83 to 17.4 per 10,000 births
- Hispanics, Asians, Native Americans, and Andeans at the higher end
- Black/African descent-least likely
- 20-40% higher in males
- Right ear-60% and unilateral 80-90%
- Vertebral anomalies, macrostomia, oral clefts, facial asymmetry, renal abnormalities, cardiac defects, microphthalmia, holoprosencephaly, and polydactyly –many are associated with Oculo-auriculo-vertebral spectrum (OAVS)



Time Period	Enrolled Participants
Day 1	30
Day 2	54
Day 3	66
Week 1	83
Week 3	100+

Study Design

Inclusion criteria:

- Parent of a child/children with microtia/atresia
- Child between 6 months-6 years of age
- Able to complete survey and interview in English

1. Survey-demographic info and other details
2. Semi-structured Interviews

Survey

Parent

- Age
- Education level
- Occupation
- Relationship to child

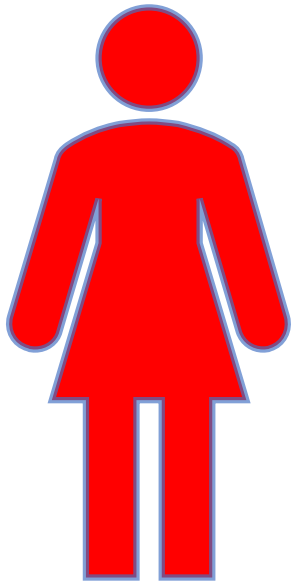
Child

- Languages used in home
 - Communication Modality
 - Gender
 - Race/Ethnicity
 - UNHS result
 - Etiology
 - NICU, medical needs
- Ear
 - Age at ABR
 - Type of HL
 - Amplification History
 - Age at Amplification
 - Early Intervention

Participants

Initial Survey N=116

Interviews for Current Study N=21



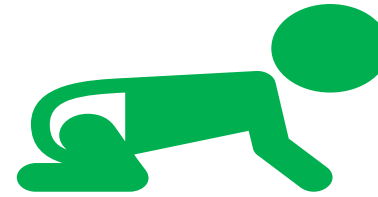
- 18 mothers, 2 both parents
- 95% had “some college” or higher
- 33% \geq 40 *yrs.*
- 76% English only homes

Child characteristics



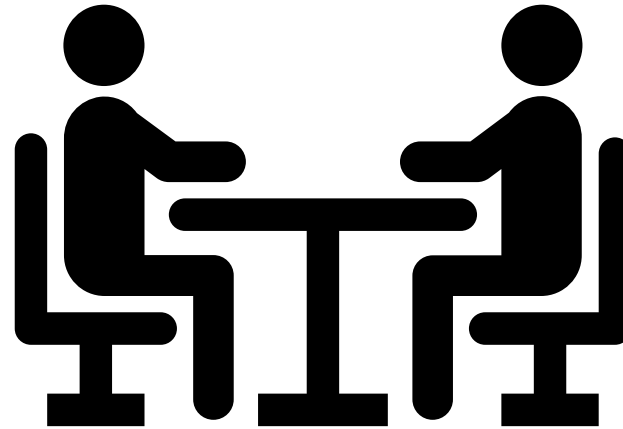
- Gender
 - Male (n=16)
 - Female (n=5)
- Ear
 - Right (n=15)
 - Left (n=4)
 - Both (n=2)
- Etiology
 - Unknown (n=19) 90%
 - Family History (n=1) 5%
 - Syndrome (n=1). 5%
- Age at ABR
 - ≤ 3 (n=18) 86%
- Type of Hearing Loss
 - Conductive (n=18)
 - Mixed (n=1)
 - **Not Sure. (n=2)**
- Amplification History
 - Uses (n=17) 64.5%
 - Never Had (n=1) 20%
 - Had but doesn't use (n=3)
- Age when dispensed:
 - 3 weeks-36 months
 - 66% received ≤ 6 months

Race/Ethnicity



White/ Caucasian (only)	16
Black/African-American or African and White/Caucasian	0
Asian or Asian bi/multiracial	2
Hispanic/Latino or Hispanic bi/multiracial	2
Asian/Hispanic multiracial	1

Interview evolution



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Initial awareness	Response/reactions of medical professionals in hospital Newborn hearing screening experience Referrals for follow up after leaving hospital
Concerns/Worries	Cause/Blame Immediate Future
Decision Making	Amplification Communication Modality Early Intervention
Supports	Sources of Information What helped Early Intervention
Advice	Professionals Other/new parents

Knowledge, support and awareness in hospitals

Reactions/responses of medical staff

“I think it was a student or a nurse or someone who wasn't really involved who told us “you'll see he has an ear deformity” After the whole fear of losing him, it was just a little traumatic how they told us but that's how we were informed.”

“I think no one in the room really knew what to say or what call it, microtia or anything right then. I think they just you know, noted that his ear didn't look normal and they brought in a NICU doctor...I think that NICU doctor said he thought they'd probably call it microtia”

“When the pediatrician came upstairs. She's looks at her ear canals-and said they're closed, we're going to have an ENT come and take a look. And that was kind of it in like the first like, I don't know, like, the immediate 30 to 40 minutes from when she was born.”

Lack of timely and accurate information

“They were saying that before you leave the hospital, an ENT will come and look at her ...we were there for 2 days and no one came. We kept asking & asking- no one ever came.”

“we didn't even know the name until like three months later until we got into see the ENT”

Dr. Google

- “The microtia part... I didn't really get anybody to explain that to me. Like this stage three thing. I didn't even find that out until I asked because we googled and I'm like, hey, there's all different kinds on here.”
- “We did our own little Google search- this is probably like this word. I don't know exactly how to say it. You know? And it looks like it's not really very harmful or, or anything. I think this is probably what it is. We got a little google research of our own. But no one said, Oh, this is microtia, this is atresia.
- “it's like a horrible thing to Google something and like the first thing it says, you know, microtia is a congenital birth defect”
- “We kind of just self-diagnosed and figured it out kind of on our own. When we left the hospital, we were pretty confident she had grade three microtia- that was purely on our own researching”

Self-blame and concerns for the future

This is my fault.

“My first thought was shit, what did I do wrong? It sounds horrible. But your first thought is, should I have eaten that or what did I cause to, you know, do to cause this?”

“You think how did I fail her? She was inside of me, what did I do that caused it? “

“I was not a drug user. I was not drinking while pregnant...which was helpful when people ask questions for me to say it wasn't my fault, because it's very easy to feel like I did something wrong during pregnancy. And that was not in fact my fault”

Concerns for the Future

“You think, what will her life be down the road? Is this going to be a burden? Is this going to make her peers tease her? You already start thinking of those thoughts”

“Everybody said he's gonna be bullied. And he will have difficulty in school if he has only one ear.”

Experience with EHDI

- “We had a very rough ABR because actually their machine wasn't working. And so we were sitting there watching and not seeing any activity. And we were just crying thinking, Okay, he's, he's deaf. That's just what our life will be we'll deal with it. And it was a young audiologist who I think was newer to the clinic or the hospital. They were both trying to troubleshoot the machine. And it it took them way too long to let us know that what's going on, we just thought he can't hear.”
- “It wasn't until I found the Facebook groups...And then I learned a lot from there. It was very shocking to see all those babies with bahas because I didn't even know that was an option for him.”

Early Intervention

- “I was asking about speech, and the EI official said he's so young, we don't do anything until we know there's problem.”
- The speech therapists were curious, because I was the only one they had. So they were more curious about how does it work kind of questions and more like asking me like a health care provider or pediatrician.”

Recommended by Parents for Professionals

- Provide parents with clear steps to follow or a single point of contact
- Increase awareness of microtia/atresia with general doctors/hospitals
- Connect new parents with a local group or other parent and share with new parents information about the Facebook groups- Microtia Parents, The Ear Community, Microtia, Adoptive Parents of Children with Microtia
- Give accurate information to new parents so that they can make informed decisions
 - ‘These are the really cool products, which one do you think he would like’
 - Benefits of Early Intervention
 - Not hearing well affects language
 - Remember: “It might hurt us at the beginning but we want the information”

Resources

- The Ear Community (Facebook and website),

Ear Community Picnics

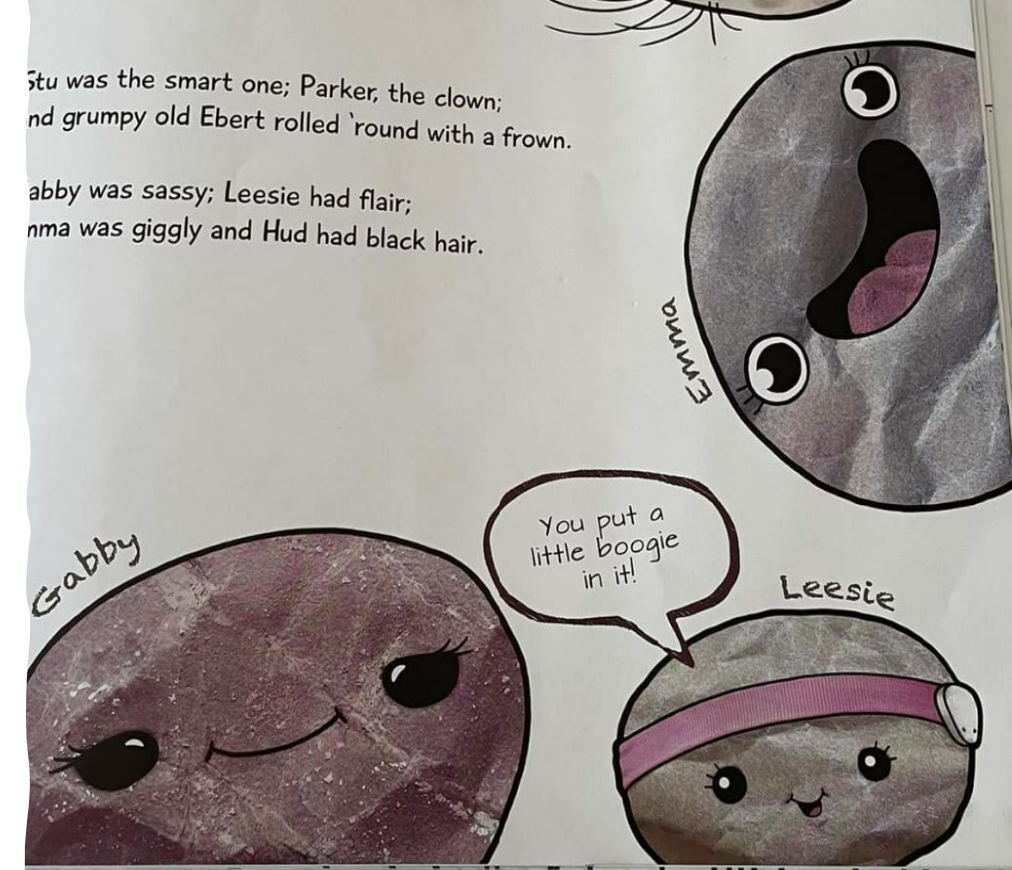
<https://earcommunity.org/events/2023-picnics-and-events/>

Facebook groups

- Microtia Parents
- Adoptive Parents of Children with Microtia/Atresia
- myFace myFace.org focus on individuals with craniofacial differences

Books

- Jojo's Tiny Ears Stefania Munzi-Logus
- Hi, I'm Me Kelly Vurinaris
- Hi, I'm Me in Kindergarten
- Ricky the Rock That Couldn't Roll Mr. Jay



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