

MICROTIA/AURAL ATRESIA: A PARENT'S PERSPECTIVE

An AudiologyOnline presentation
Sponsored by Oticon Medical



PRESENTED BY: MELISSA TUMBLIN

- o A parent of a child born with right sided Microtia and a unilateral hearing loss caused by Atresia.
- o Parent Advocate
- o Founder of the Microtia and Atresia Support Group
- o Founder of Ear Community, a 501(c)(3)
- o Board of Director Member for Hands & Voices
- o Past Family Advisory Council Member for Children's Hospital Colorado
- o Medical Device Marketing Professional

PRESENTATION GOALS

- . Discuss the lack of awareness about Microtia and Atresia
- . Discuss the impact of unilateral hearing loss on the pediatric patient
- . Discuss the treatment options for the pediatric patient who has Microtia/Atresia
- . Discuss helpful networks for individuals who have Microtia and Atresia

OUTLINE

- Microtia and Atresia in review
 1. History
 2. Current options
- My child has congenital Microtia/Atresia, now what?
 1. The diagnosis and search for answers
 2. Shared experiences
 3. Where to begin with a child who is born with Microtia and Atresia

4

OUTLINE

- Unilateral hearing loss – Is one good ear good enough?
 1. The critical years of development
 2. Spatial hearing/sound localization
 3. Challenges in the school classroom

5

OUTLINE

- Treatment options
 1. Bone anchored hearing devices and systems
 - a. Implantable surgery or a softband head band?
 - b. At what age? - A standard or personal preference
- FM Systems and other helpful technology
- Networking and helpful resources

6

MICROTIA AND ATRESIA IN REVIEW



- Microtia is a congenital deformity affecting the outer ear (pinna) where the ear does not fully develop during the first trimester of pregnancy.
- Aural Atresia is the absence or closure of the external auditory ear canal.

7

Microtia and Atresia in Review

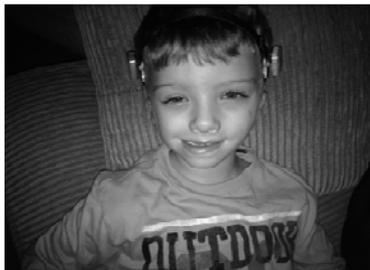


Grade I Grade II Grade III Grade IV

Permission to post the following images has been granted by Dr. Sheryl Lewin, M.D. Medpor surgeon.

8

MICROTIA AND ATRESIA IN REVIEW



Hemifacial Microsomia

Permission to post the following image has been granted by this child's parents.

9

MICROTIA AND ATRESIA IN REVIEW

- 1 out of every 6,000 to 12,000 births.
- More common in males.
- More common for the right ear to be affected.
- Microtia and Atresia can be unilateral or bilateral.
- Conductive hearing loss due to Atresia.
- Ethnicities affected by Microtia/Atresia.
- In 2012, approximately 4 million babies were born in the United States with about 500 to 600 of these births having Microtia and Atresia. It is estimated that 39,000 people live in the United States with Microtia/Atresia.
- Genetic???

10

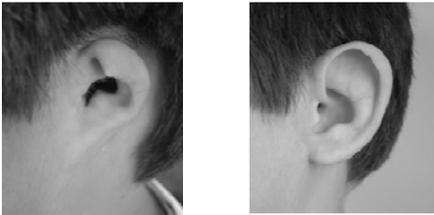
MICROTIA AND ATRESIA IN REVIEW



Microtia ears are beautiful ears

11

MICROTIA AND ATRESIA IN REVIEW



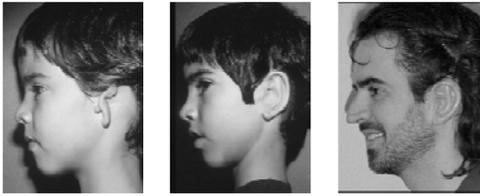
Prosthetic Ear

- Realistic • Non-surgical option • Temporary

Permission to post the following images has been granted by Greg Gion, anaplastologist.

12

MICROTIA AND ATRESIA IN REVIEW



Rib Graft: The Gold Standard

- Age 5 • 3 or > surgeries • Biological material

Permission to post the following images has been granted by Dr. Burt Brent, M.D. Rib Graft surgeon.

13

MICROTIA AND ATRESIA IN REVIEW



Medpor

- Age 3 • Achieved in one stage • Polyethylene

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14

MICROTIA AND ATRESIA IN REVIEW



Canalplasty (atresia repair)

Permission to post the following image has been granted by Dr. John Reinisch, M.D. Medpor surgeon and Dr. Joseph Roberson, M.D. Canalplasty surgeon (combined surgery).

15

MY CHILD HAS MICROTIA AND ATRESIA – NOW WHAT?



3.5 years old, Grade III Microtia and Atresia of the right ear.

16

EXPERIENCES WITH MICROTIA/ATRESIA

"My daughter, Eden, was born with RMA in September (2010). **At our first ENT visit 'the best' doctor in Omaha wasn't going to mention a BAHA until I brought it up.** Eden is being fitted for her first BAHA in 2 weeks."

- Jay, Nebraska (9/2010)

17

EXPERIENCES WITH MICROTIA/ATRESIA

"...My daughter Makayla was born with right ear microtia and atresia. When she was born, I had no idea what was going on, what caused her condition or [found] physicians that were familiar with Microtia. No one advised me on hearing devices or options other than reconstructive surgery. **After 9 years, Makayla is finally getting a bone conductive hearing device. I am appalled that no audiologists and ENTs have suggested them to us before.**"

- Cate, Texas (10/2012)

18

EXPERIENCES WITH MICROTIA/ATRESIA

"I am both a professional in the field...and the parent of a child with bilateral microtia/atresia. This population of children are, overall, overlooked, undeserved, poorly researched, and under amplified. That statistics for the incidence of microtia/atresia are ridiculously in accurate- and yet no one is correcting them. **The advice given to parents is often inadequate and often outdated.** The youngest child to date that we have fit with a baha was 21 days old. The second youngest was about 6 weeks old. If the advice for other types of hearing loss focus on the earlier the better and two are better than one, why are the families of these children not counseled the same way?"

- Meredith, New York (10/2012)

EXPERIENCES WITH MICROTIA/ATRESIA

"Once I found out about a BAHA, I called my hearing center and got a loaner within a month. **The Audiologists say the earlier the better and nobody ever even mentioned a hearing device for babies.**"

- Casey, Texas (11/2012)

EXPERIENCES WITH MICROTIA/ATRESIA

"My daughter is 3 1/2years old and for the first time today I feel like we have direction and are getting somewhere with her microtia and atresia. **Today Sophia was fitted for a soft band Baha which we weren't informed was an option...I was also able to get in touch with a doctor at Shriners Hospital who made us feel very hopeful about having medpor surgery done which again I did not know about.**"

- Melissa, Illinois (5/2011)

EXPERIENCES WITH MICROTIA/ATRESIA

"I thought there was no one like me that was born with Microtia. I ALWAYS wanted to meet people just like me. For many years up until my age now (33) in Columbia, SC I thought that I was alone. I don't have much anger but I am frustrated with what I have going on and that's hearing."

- Angela, South Carolina (12/2012)

EXPERIENCES WITH MICROTIA/ATRESIA

"In spite of believing for my entire life that I was deaf in my left ear, I learned there may now be a possibility of hearing! There is more testing required, and will require the BAHA. I am not sure what will come of this. I am still in shock over this news, and can only imagine how life changing this can be for others!"

- Angela, Canada (10/2011)

EXPERIENCES WITH MICROTIA/ATRESIA

"We both cried when we realized that Natalie would be able to meet other children just like her and that I would be able to meet other parents who share the same experience. Natalie has chronic ear infections and I was worried that she couldn't hear. **For the past five years, I was told by our doctors that Natalie could not have a Baha until she was five years old.** Even though I was sad to learn that she could have been aided sooner with a soft band at the picnic, I am happy to say that Natalie finally does have a Baha today and she loves it!

- Bliss, Colorado (10/2012)

EXPERIENCES WITH MICROTIA/ATRESIA

"Our 3 year old daughter...has unilateral Microtia. We have been seeing Dr. [] at [] since she was born. It wasn't until about a week ago we found out on our own about Medpor as well as your website. **We wished we would have been told about other options besides rib graft and prosthetics.**

- Scott, Colorado (8/2012)

EXPERIENCES WITH MICROTIA/ATRESIA

"Noah has RMA and he passed his newborn hearing test too. Later as a toddler I realized he was having hearing and speech problems. **We didn't find out he had atresia till he was almost five. Because of that newborn hearing screen I felt that not only did it give a false sense of hope but it delayed in getting the help he needed.**"

- Amanda, Texas (1/2013)

EXPERIENCES WITH MICROTIA/ATRESIA

"In 2006, we had no real idea what was up with my daughter's LMA ear. **We found out over the internet then we had to make the call to get more screening through our local kids hospital's audiology dept.**"

- Jenn, Canada (1/2013)

EXPERIENCES WITH MICROTIA/ATRESIA

"When my daughter was born, the Pediatrician saw her ear during the exam but she "passed" the hearing test in both ears! We even received a copy of the results. **She has stage three and no canal opening at all, so it was obvious she couldn't have passed.**"

- Misty, Arizona (1/2013)

WHERE DO I BEGIN?

1. Diagnosed with Microtia and Atresia
 - a. The mother should never blame herself
 - b. Informed about helpful resources
2. Renal ultrasound and EKG/ECG
3. Diagnostic assessments:
 - a. New born hearing screening
 - b. ABR and (AOE) Auto-acoustic evaluations
4. Meet with an ENT and Audiologist
 - a. Discuss Microtia and Atresia
 - b. Discuss options and hearing solutions
 - c. Discuss monitoring hearing loss

UNILATERAL HEARING LOSS

Is unilateral hearing loss misunderstood?

- . The signs
 - the evaluation
 - speech and communication delays
 - realizing my child needs help
 - understanding hearing loss
 - helpful services and options

UNILATERAL HEARING LOSS

"Unilateral Hearing Loss in Children: Challenges and Opportunities

By, Oyler, R. and McKay, S.
(The ASHA Leader, 1/22/2008)

"Studies show that even before they enter school, children with UHL are at risk for speech and language delays. Although the average age for first words was found to be within normal limits (12.7 months), the average age for the first two-word utterances was found to be significantly delayed in children with UHL (Kiese-Himmel, 2002)."

UNILATERAL HEARING LOSS

"Supplement to the JCIH 2007 Positions Statement: Principles and Guidelines for Early Intervention After Confirmation that a child is Deaf or Hard of Hearing"
(Pediatrics, Vol. 131, No. 4, 4/2013, pg.9)

"Research indicates that there are sensitive periods for the development of auditory skills and spoken language, specifically, the first 5 years of a child's life are critical for development in these areas. To optimize this short time period of a child's life, families and infants/children who are D/HH require the highest level of provider skills at the very beginning of the child's life."

SPATIAL HEARING/SOUND LOCALIZATION

"Why Our Two Ears Process Sound Differently"
By, Dr. Neil Bauman, Ph.D.
(4/2/2006)

"Therefore, only having one ear detracts from our ability to hear, understand, and appreciate sound."

SPATIAL HEARING/SOUND LOCALIZATION

"Unilateral Hearing Loss – How Serious Is it?"

By, Jane Madell, Editor
(Hearing and Kids, 3/2012)

"Brain research has demonstrated that language is a left brain activity and the majority of fibers from the right ear go to the left side of the brain so, if a child is going to have a hearing loss in one hear, it would be better if it were the left one. (If only we could control this.)"

37

SPATIAL HEARING/SOUND LOCALIZATION

"Understanding Single Sided Deafness: Evaluation and Treatment for Professionals"

By, Dr. George Cire, AuD
(Online HOPE Series 8/2012)

"First, you lose the ability to have spatial hearing, or what we traditionally think of as localization in the horizontal plane. Our two-eared auditory system is precisely oriented for using specific cues that allow us to localize sound, and we use a two-ear input system to make that happen. When one ear is taken out of the equation, it creates some confusion within the brain."

38

SPATIAL HEARING/SOUND LOCALIZATION

"The loss of spatial hearing not only heightens communication concerns, but it also creates safety concerns."

By, George Cire, AuD
(Online HOPE Series 8/2012),



39

CHALLENGES IN THE SCHOOL CLASSROOM

"Unilateral Hearing Loss in Children: Challenges and Opportunities"
By, Bess & Tharpe (1984), Oyler, Oyler, & Matkin (1988) and McKay, S.
(The ASHA Leader, 1/22/2008)

"Children with UHL were approximately 10 times more likely to fail a grade than their normal hearing peers."

CHALLENGES IN THE SCHOOL CLASSROOM

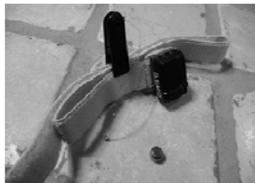
"One third of children with unilateral hearing loss had to repeat a grade by 3rd grade."

As demonstrated by, Bess et al (1998), Bess et al (1986)
English and Church (1999)

"While a unilateral hearing loss may not be the same kind of emergency that a bilateral hearing loss is, auditory brain development is just as critical for these children." By, Jane Madell, Editor, (Hearing and Kids, 3/2012).

TREATMENT OPTIONS

Bone Anchored Hearing Devices and Systems



Cochlear BP100
BAHA3



Oticon Medical
Ponto Pro

TREATMENT OPTIONS

Bone Anchored Hearing Devices and Systems

- 1. Bone Anchored Hearing Aid (BAHA)
- 2. Bone Conduction Hearing Aid (BCHA)
- 3. Bone Conduction Hearing Device
- 4. Osseointegrated Implant System
- 5. Sound Processor

43

TREATMENT OPTIONS

Bone Anchored Hearing Devices and Systems

- Implantable Surgery after 5 years of age
- Mandated by FDA

Permission to post the following images has been granted by Oticon Medical.
 Permission to post Oticon Ponto Pro snapped in has been granted by patient.
 Healing cap image was sourced from www.entkent.com



44

TREATMENT OPTIONS

Bone Anchored Hearing Devices and Systems

Softband Head Band

- Can be used on children under 5 years of age



45

TREATMENT OPTIONS

Bone Anchored Hearing Devices and Systems
Softband Head Band

- Standard or personal preference?
- Recommended age?
- Regional?

46

FM SYSTEMS

- Helps with speech
- Helps in the classroom setting
- Helps allow children to meet and exceed expectations in the classroom



Pictured: Oticon Medical Ponto Pro w/Amigo FM System and Phonak Inspiro FM System with Oticon Ponto Pro

47

OTHER HELPFUL TECHNOLOGY

Helpful Hearing Devices for Conductive Hearing Loss

- Oticon Medical Ponto, Ponto Pro, and Ponto Pro Power, www.OticonMedical.com

- Cochlear BP100, BP110 Power, www.Cochlear.com

- Sophono Alpha 1 and Alpha II, www.Sophono.com

- MedEl Soundbridge and Bonebridge, www.Medel.com/us

- Sonitus Medical Soundbite, www.SoundBiteHearing.com

- BMH Tech Contact Mini, www.BHM-TECH.at

- TransEar TransEar, www.TransEar.com

- FM Systems by Phonak Inspiro, www.Phonak.com and the Oticon Medical Amigo, www.OticonMedical.com

48

EAR COMMUNITY



Global Microtia and Atresia Summer Family Picnics

2013 EAR COMMUNITY PICNICS



- oOrlando, Florida – April 27, 2013
- oColumbus, Ohio – June 22, 2013
- oLondon, England – June 29, 2013
- oBarcelona, Spain – July 6, 2013
- oChicago, Illinois – July 13, 2013
- oBroomfield, Colorado – July 27, 2013
- oLos Angeles, California – August 10, 2013

HELPFUL ARTICLES AND DOCUMENTS BY MELISSA TUMBLIN

Document: Comparative Review for the Cochlear BP100/BAHA3, Oticon Ponto Pro, and Sophono Alpha 1 (S) Soft Band Head Band BAHAs Models, August 2011, revised October 2011. Posted to various surgeon websites and on hand at medical centers that specialize in Microtia and Atresia repair. by Melissa Tumblin.

Document: "10 Helpful Tips for BAHAs Wearers," posted to various websites, and support groups that help with Early Intervention service programs. September 2011, by Melissa Tumblin.

Article: "Falling Through the Cracks With Microtia/Atresia," published by Hands & Voices, Winter 2010, Volume XIV – Issue 2 of "The Communicator," by Melissa Tumblin.

Link to article: http://www.handsandvoices.org/articles/early_intervention/v14-2_cracks.htm

Article: "Mixed Feelings: Making Surgical Decisions for Children With Microtia and Atresia," summer 2011, Volume XIV - Issue 4, pg. 19 of the National issue for "The Communicator" published by the Hands & Voices Organization, by Melissa Tumblin.

Press Release: On February 8, 2012, a press release announcing the launch of the Ear Community website was picked up by multiple business and news wire entities such as: Healthy Hearing, AudiologyOnline, Hearing Review, Advance for Hearing Practice Management, Hearing Health Matters, etc...

Article: "A Little Love Can Go a Long Way" in the "Facing Forward" newsletter for the AboutFace Organization's international newsletter. April 2012, Vol. 10, ISS.2, by Melissa Tumblin.

Interview: Interview with "Melissa Tumblin, Founder, Ear Community" through AudiologyOnline, archived, July 16, 2012. Link to interview: <http://www.audiologyonline.com/interviews/interview-with-melissa-tumblin-founder-6955>

Please visit www.EarCommunity.com for additional helpful articles on hearing loss under the Hearing Loss Menu tab. 54

Thank you!

Ear Community

www.EarCommunity.com

E-mail: EarCommunity@gmail.com

The Microtia and Atresia Support Group on Facebook
