



# NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

## NOVEMBER 9, 2021

### SUPPORT FOR NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

“I’m honored to introduce this resolution in Congress, and to build on the advocacy and passion that my constituents Ally and Melissa have been growing in Colorado,” said **Congressman Joe Neguse**. “Ally’s bravery and ingenuity to write our office and share the idea behind Ally’s Act has begun a movement in Congress to expand access to specialized hearing devices and support individuals with microtia and aural atresia. This resolution, establishing November 9th as National Microtia and Atresia Awareness Day will continue to build awareness and help more families to leave the hospital equipped with answers for navigating these health conditions.”

“Misinformation or the lack of information about microtia and aural atresia leave far too many Americans behind,” **Senator Warren** said. “That’s why I’m glad to introduce this resolution to raise awareness of microtia and aural atresia, and advocate for the community of children and adults who are affected by these health conditions so that every individual with microtia and aural atresia can flourish.”

“So many of us often take for granted the ability to hear, as well as how we use our senses to effectively communicate. Establishing November 9 as Microtia and Atresia Awareness Day will help bring needed attention to this condition, while also shining a light on the hearing-loss community. We must continue to advocate on behalf of those who are impacted by Microtia and Atresia, and we must make sure that resources continue to be available to individuals who are without hearing or hearing impaired,” **Senator Capito** said.

“I am proud to join my bipartisan colleagues to formally recognize National Microtia and Atresia Awareness Day,” said **Rep. Fitzpatrick**. “Today, we have an opportunity to not only celebrate the children and adults living with microtia and aural atresia, but also, build public awareness and support for these rare but treatable conditions.”

**Melissa and Ally Tumblin, Founders of the Ear Community Organization:** “It is important to have national awareness days that raise awareness, encourage research and promote education about unique and rare congenital anomalies like Microtia and Aural Atresia (when a child is born with missing or underdeveloped ears and no ear canals, resulting in hearing loss). We welcome National Microtia and Atresia Awareness Day - as a day to shine a light on this rare cause, but also a day to share options and resources that can improve the quality of life for the children and adults born with Microtia and Aural Atresia. This awareness day is also meant to help the children and adults born with Microtia and Atresia know they are beautiful and never alone.



# NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

## NOVEMBER 9, 2021

Along with families, medical professionals, educators, therapists and advocates we look forward to embracing National Microtia and Atresia Awareness Day every November 9<sup>th</sup>!”

**Leslie Gonsette, MD, Internal Medicine & Pediatrics Board Certified, Ear Community Board Member:** “As a pediatrician and mother of a child born with Microtia and Atresia of her right ear, I embrace National Microtia and Atresia Awareness Day as a wonderful means of promoting awareness and education. Microtia & aural atresia doesn't have to negatively impact those affected, thanks to the support and information gathered by incredible organizations, health care professionals and parent advocates. It's important to recognize this by a nationally recognized day for Microtia and Atresia. With the right hearing devices and support, children and adults may go on to live normal, productive and happy lives, like my thriving little girl who is now six years old.”

**Rachel Bernhard, Ear Community Board Member:** “As a Board Member for Ear Community and someone who was born with Microtia and Atresia, I personally know the struggles that these individuals face daily and how important it is to have a day that creates a sense of community and awareness for this rare condition that is not well known. National Microtia and Atresia Awareness Day reminds people to have compassion and kindness for those who look different and patience for those who cannot hear well. This day also raises awareness of the problems that arise for those with hearing loss and the importance of passing legislation that supports overcoming such challenges.”

**Jonathan G. Seidman, PhD, Seidman Laboratory – Genetics:** “The Seidman laboratory in collaboration with Roland “Ron” Eavey, MD, SM and the "Ear Community" have been studying the condition for the last 30 years in a medical and scientific research effort to expand the clinical knowledge of and identify the genetic causes of microtia and aural atresia. Our research team recognizes the importance of promoting educational awareness of Microtia and Aural Atresia, as well as the need for continued research to learn more about the causes and treatment of this condition which affects over 750,000 individuals and their families worldwide. Patients and their family members can experience isolation and loneliness as they struggle for information, medical help and treatment of a rare diagnosis. We are awed by the strength, resilience and dedication shown by the Ear Community and we are honored and humbled to partner with them and applaud their efforts in erasing any stigma associated with microtia and aural atresia. On behalf of the Seidman Laboratory we are pleased to endorse the designation of National Microtia and Atresia Awareness Day, and to celebrate and express our support for the community of children and adults with microtia or aural atresia. We embrace the day as a much-



# NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

## NOVEMBER 9, 2021

needed opportunity for support and recognition of this community as well as the families, teachers, advocates, and medical professionals from around the world who are working to foster awareness and support to improve the lives of those affected by Microtia and Aural Atresia.”

**Mai Thy Truong, MD and Kay W. Chang, MD, Stanford Children’s Health, Pediatric Otolaryngology, Head and Neck Surgery:** “National Microtia and Atresia Awareness day sheds light on this rare condition that deeply affects many patients and their families. Increasing awareness may ease the burden for those children, adults and their families to live without shame or embarrassment and remove the stigma of having underdeveloped or missing ears. Stanford Microtia and Atresia Clinic supports National Microtia and Atresia Day and is proud to be a source of education on this important congenital disorder. We are proud to embrace the Microtia and Atresia community alongside The Ear Community Organization every November 9th.”

**Tony Manna, President, Cochlear Americas:** “On behalf of Cochlear Americas, we are thrilled November 9 will be known as National Microtia and Atresia Awareness Day, and we commend Ear Community’s dedicated, passionate efforts to bring awareness and support to the needs of families of children born with Microtia and Atresia. We are honored to partner with Ear Community to provide access to sound through our hearing technology, so children impacted by hearing loss can have the opportunity to connect with others and live a full life. Thank you Ear Community for all that you do.”

**John F. Reinisch, MD, Professor of Surgery, Keck School of Medicine – USC, Director, Craniofacial and Pediatric, Plastic Surgery, Cedars-Sinai Medical Center:** “As a microtia surgeon, I am excited to support November 9th as National Microtia and Atresia Awareness Day. Microtia/Atresia is congenital anomaly that can have a profound impact on a child’s development. Because it is uncommon, treatment for microtia and it’s hearing loss is inconsistent and often suboptimal, limiting the potential of children with this condition. National Microtia and Atresia Awareness Day will shine a needed light on this anomaly and hopefully lead to improved understanding and treatment of these children.”

**Alan Raffauf, MA, Vice President of Marketing, Oticon Medical, LLC:** “As a long-time supporter of the Ear Community Organization and a proponent for the treatment of hearing loss, Oticon Medical is honored to have the opportunity to endorse the resolution declaring November 9<sup>th</sup> National Microtia and Atresia Awareness Day. When left untreated, Microtia and Aural Atresia can have devastating effects on an individual’s social, educational and emotional wellbeing. However, with proper intervention by caring professionals and the application of



# NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

## NOVEMBER 9, 2021

technology developed to treat microtia and atresia, these same individuals can overcome their challenges and live incredibly full and wonderful lives. Oticon Medical is committed to continuing our development of solutions for those with Microtia and Atresia and we are thrilled to see efforts such as a day of national awareness proposed to bring attention to these rare but treatable conditions.”

**Lisa Cannon, 2021 President, Educational Audiology Association:** “As audiologists working with children in the school setting, we often see the isolation and misunderstanding that students with ear and hearing differences experience. "National Microtia and Atresia Awareness Day" is a wonderful opportunity to show our students that they are not alone and they belong to a worldwide community of others who share their experience. We look forward to participating in the effort to raise awareness and are excited to celebrate with the entire community every November 9th!”

**Sheryl Lewin, MD, Craniofacial and Pediatric Plastic Surgeon specializing in Microtia Lewin Ear Reconstruction:** “National Microtia and Atresia Awareness Day helps bring attention to this specific condition and its associated hearing loss. It provides individuals with uncommon craniofacial differences a vehicle to educate family, friends, strangers and medical professionals in order to foster increased acceptance and understanding. This day also unites the Microtia and Atresia community, reassuring one another that they are all beautiful, special and not alone!”

**Alicia Spoor, AuD, Academy of Doctors of Audiology, Advocacy Chair:** “The Academy of Doctors of Audiology (ADA) is pleased to support Congressman Neguse’s efforts to raise awareness of microtia and atresia and embrace National Microtia and Atresia Awareness Day,” said Alicia Spoor, Au.D., ADA Advocacy Chair. “Audiologists work closely with individuals, their support system, and other professionals to diagnose and treat microtia and atresia. Having an awareness day is invaluable in promoting positive changes in the attitudes, inclusivity, and behaviors among the public—and the valuable research and advancements that support the best care for people with microtia and atresia.”

**James C. Denny, III, MD, AAO-HNS, EVP/CEO:** “The American Academy of Otolaryngology-Head and Neck Surgery congratulates and thanks the organizers and participants involved with the National Microtia and Atresia Awareness Day for drawing attention to this treatable congenital birth defect and promoting education and treatment for these patients and their families.”



# NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

## NOVEMBER 9, 2021

**Noel Jabbour, MD, MS, FACS, Pediatric Otolaryngology:** “Individuals and families affected by Microtia and Aural Atresia have often never met another person with this condition until the diagnosis is made at birth. Microtia and Atresia can have a significant impact on hearing, speech, and personal interaction with others. Families are often not aware of the many excellent treatment options available. I am thrilled to support November 9 as Microtia and Atresia Awareness Day. This will have a critical role in promoting awareness about this condition and educating all who may be affected by, care for, or interact with individuals with Microtia and Aural Atresia”

**Siva Chinnadurai MD, MPH, Medical Director, Ear Shape Clinic- Children’s Minnesota:** “Families faced with the diagnosis of microtia and/or atresia often feel alone, without clear direction or advocacy. In my practice I routinely see the detrimental impacts of this feeling of isolation. The inception of National Microtia and Atresia Awareness Day will be a tremendous step in letting these children and families know that they are seen and heard, and that there is a community of advocates and health professionals dedicated to supporting them.”

**Roland “Ron” Eavey, MD, SM, Pediatric Otolaryngologist:** “Microtia is a congenital malformation of the external ear which affects appearance and atresia means that the ear canal remains sealed which diminishes hearing. Considerable research and clinical progress has been made so that microtia and atresia are ‘role model’ examples of how awareness, community action and science synergize at the family as well as national level.”

**Carolyn Smaka, AuD, Editor in Chief, AudiologyOnline:** “Microtia and atresia can impact all aspects of a person’s life, including language and communication, as well as social and emotional well-being. By creating a national day of awareness, we can best educate healthcare professionals, teachers, and the general public about this rare genetic condition. This helps to create more compassionate and supportive communities, and helps ensure that individuals and families affected by microtia and atresia get access to the many life-changing resources now available.”

**Drs. David Shaye, Alicia Quesnel, Michael Cohen, and Theresa Hadlock, Mass Eye and Ear, Microtia and Atresia Center:** “Clinicians at the Massachusetts Eye and Ear are proud to acknowledge and support the National Microtia and Atresia Awareness Day initiative. This milestone will bring yearly focus to a condition affecting hearing health and overall wellbeing of a population whose challenges will be more thoroughly addressed through effective research, along with medical and surgical innovations.”



# NATIONAL MICROTIA AND ATRESIA AWARENESS DAY

## NOVEMBER 9, 2021

**Brian Rodgers MD, Otology, Neurotology, and Skull Base Surgery, Dallas Ear Institute:**

“Microtia and atresia are uncommon conditions that cause congenital hearing loss. Due to a lack of awareness of these conditions, many children experience delay in diagnosis, barriers to treatment, and impaired development of hearing, speech, language, and communication skills. I am very excited that November 9th is National Microtia and Atresia Awareness Day. This will be a tremendous step forward in addressing the care of these children.”

**J. Arturo Bonilla, MD, Founder, Microtia Congenital Ear Deformity Institute:**

“I am writing to encourage you to please support National Microtia and Atresia Awareness Day. As a practicing pediatric microtia surgeon for over 25 years, I have seen thousands of children affected by this ear malformation and associated hearing loss. These children are changing the lives of others around them because of their courage and tenacity as they undergo surgical reconstruction to correct their ear malformation and hearing loss. This special day would bring such needed awareness of this condition.”

**Angelo Leto Barone, MD, Johns Hopkins trained plastic surgeon who is currently the Craniofacial and Pediatric plastic surgery fellow at the Cincinnati Children’s Hospital Inventor of a new device for microtia repair that is currently being used for autologous microtia repair:**

“I am ecstatic to learn that patients with microtia and atresia have now a day dedicated to create awareness towards their conditions. As a plastic surgeon who has a particular interest in treating these patients, I hope this day allows people to learn about the condition and other facial differences, and raise awareness at the Federal level to grant full cost coverage of hearing devices that allow these children to have a normal life.”