



**‘Protecting Young Ears: Navigating Disease & Medication Risks’ – A Reflection Paper
A National Deafness Sector Summit
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Strengthening the Bridge: Hearing Health as a Priority

"Hearing loss is one of the most common sensory disabilities worldwide, it affects around 34 million children." – Dr Duaa Gaafar

On November 15, 2024, we gathered at the National Deafness Sector Summit, an event organised by Deafness Forum Australia, to advance our goal of making hearing health a national priority for all Australians, at all stages of life.

It's an ambitious goal, but one we believe is worth striving for. The Summit was a space for meaningful dialogue and action, where experts and community came together to discuss the urgent need to prevent hearing loss.

The theme, '*Protecting Young Ears: Navigating Disease & Medication Risks*,' sparked essential discussions on the silent threats to babies, children, and youth. In particular, we focused on hearing loss caused by congenital cytomegalovirus (cCMV) and the use of certain antibiotics.

Through expert presentations and personal stories, the Summit underscored a vital message: hearing health isn't just a medical issue—it's a national priority that demands immediate action.

Hearing is a bridge.



Just as a bridge connects us to the world around us, our ability to hear connects us to others. The threat of hearing loss is like losing that bridge, isolating us from communication and experience. The Summit highlighted that if we want to protect the future of our children, we must ensure this bridge remains intact.

We were honoured to bring you leaders such as Dr. Duaa Gaafar from Murdoch Children's Research Institute, A/Prof Hayley Smithers-Sheedy, Kath Swinburn, and Pam Rogers from Cerebral Palsy Alliance. Their expertise on the hidden dangers of cCMV and antibiotic-induced hearing loss emphasised one key point: the time to act is now.

While we're proud of the Summit's success, we believe reflection is important—deepening critical conversations, helping the community consider next steps, and reinforcing our commitment to actions that will prevent hearing loss. This reflection paper ensures we stay focused on making hearing health a national priority for all Australians.

The Sword & The Silent Intruder: What We Learned

This Summit presented invaluable insights from leading experts on preventing hearing loss in children.

Every step we take to reduce the risk of irreversible hearing loss is a step toward preserving a child's ability to thrive, learn, and connect with the world.

Presentation 1: Antibiotics and Hearing Loss in Children



Presented by: Dr Duaa Gaafar, General Paediatrician & Clinical Pharmacologist from the Department of General Medicine | Royal Children's Hospital | Murdoch Children's Research Institute

"With this [antibiotic caused] damage, it's usually a severe and profound hearing loss, and it's irreversible." – Dr Duaa Gaafar

Antibiotics & Hearing Loss – 5 Fast Facts:

1. **40%:** Aminoglycoside antibiotics cause hearing loss in up to 40% of children treated, but Australia lacks national hearing screening guidelines for prolonged use.
2. **Key Risk Factors:** Dosage, treatment duration, kidney function, age, blood levels, and genetics influence hearing loss risk.
3. **Genetic Testing:** While potentially useful, genetic tests

for hearing loss risk may not be cost-effective and can produce false positives.

4. **75-83%:** Model-Informed Precision Dosing (MIPD) can reduce side effects studies show and achieve target drug concentrations in **75-83%** of cases.
5. **More Research Needed:** Further studies are needed to improve identification of high-risk populations, better understand and mitigate antibiotic-related hearing loss.

Antibiotics is a double-edged sword.



Just as a sword can be wielded for both protection and harm, antibiotics have the power to save lives, but without appropriate protective measures can lead to hearing loss. Precision dosing and genetic testing can help us wield this sword more responsibly, balancing the benefits with the risks.

A powerful takeaway for us is that the future of paediatric care lies in personalised medicine. Through identifying high-risk populations, precision dosing, and careful genetic screenings, we can safeguard the hearing and the future of our children.

And that the greatest power clinicians hold isn't just in curing diseases, but in preventing lifelong challenges. With the right knowledge and tools, we can stop some forms of hearing loss before it ever begins.

Presentation 2: Congenital Cytomegalovirus Opportunities for Prevention



Presented by: A/Prof Hayley Smithers-Sheedy, MPH, PhD, Principal Research Fellow from Cerebral Palsy Alliance, The University of Sydney



Kath Swinburn, MPH, Research Officer & Ethics Governance Manager from Cerebral Palsy Alliance, The University of Sydney



Pam Rogers, passionate disability advocate and devoted mother.

“Congenital CMV is much more common than we might realise. In fact, it’s the most common infectious cause of disabilities of babies in Australia. CMV cause 1 baby born every day with lifelong disabilities due to this virus.” – A/Prof Hayley Smithers-Sheedy

“Unfortunately, Australian research also tells us, though, that awareness of CMV is shockingly low. So, we know that only 20% of pregnant women have ever heard of CMV, and we also know that [only] 10% of maternity health professionals in Australia routinely report that they discuss CMV prevention with pregnant women and families in their care.” - Kath Swinburn

“It’s ludicrous that we’re not talking to women about this.” – Pam Rogers

CMV & Hearing Loss – 5 Fast Facts:

1. **50%:** About 50% of people will contract CMV by young adulthood, often without symptoms or only mild flu-like symptoms. Children, due to poor hygiene, are common transmitters.
2. **2 at-risk groups:** CMV mainly affects immunocompromised individuals and pregnant women.
3. **20-30%:** CMV causes 20-30% of sensorineural hearing loss in children, with progressive and fluctuating loss that can develop years later.
4. **Leading cause:** CMV is the leading non-genetic cause of sensorineural hearing loss globally, more common than rubella or toxoplasmosis.
5. **Prevention:** Primary prevention may involve a vaccine (under research), hygiene practices or following guidelines, secondary

prevention includes antiviral drugs like valacyclovir (in trials) and screening pregnant women for CMV to administer antiviral treatment, and tertiary prevention includes administering antiviral drugs to infants.

CMV is a silent intruder.



CMV often enters the body without warning, much like a silent intruder. Without awareness and proactive steps, it can wreak havoc on children's hearing and development. But just as we lock doors to prevent unwanted entry, we can take preventive measures to stop CMV in its tracks.

One powerful takeaway is that the strength of a community lies in its ability to protect its most vulnerable. CMV is preventable, and we have the chance to lead the way. Hope is active, reflected in the daily actions we take to prevent what we can and help children thrive.

Prevention and early intervention are key. With the right resources and awareness, we can avoid countless cases of hearing loss.

Pam Rogers' emotional story of her son Christopher, who brought joy to their family despite his CMV diagnosis, underscores the ongoing challenges families face. While Pam wouldn't change her son, she wouldn't wish this journey on any other family. Timely interventions and simple preventative steps can transform a child's future.

This presentation reminded us that together, we can shift the narrative around CMV—

from ignorance to awareness, and from risk to prevention. A well-informed community is the most powerful tool we have in safeguarding the future of our children.

Lighting the Way: What the Community Said

Knowledge is light.



The Summit filled gaps in understanding of CMV and antibiotic-induced hearing loss. Awareness can turn on the light and guide future directions.

We're pleased that the feedback from the Summit was overwhelmingly positive, with attendees describing the experience as "insightful," "informed," and "inspired." With around 100 participants, many found the presentations to be not only useful and relevant but of high quality, meeting their expectations. It was heartening to hear that many plan to apply the insights in their own work, share them with others, or pursue further learning.

Yet, the key takeaway for all of us was clear: there is still much more to be done to prevent hearing loss caused by CMV and antibiotics.

Some of the key reflections from the community include:

- "We do not know enough about the effects of antibiotics and the risks associated with them. We should have education programs around the risks of CMV."
- "There are straightforward and practical steps that the community can take to reduce the risks."
- "We have a lot more work to do for our pregnant women and unborn

babies in this space to prevent the spread and effects.”

- “The alarmingly low numbers of awareness of women & health professionals - need to improve that.”

We agree. There is a clear need for more education, prevention, and action. Together, we can make significant strides in protecting our children and the broader community

Mosaic Of Efforts: Understanding the Deeper Implications

The Summit revealed that hearing health is not just a medical issue—it’s a societal one, affecting families and communities across the country. While challenges remain—such as the lack of understanding about genetic variants and the need for better public awareness of CMV—there are many steps we can take now to begin making a difference.

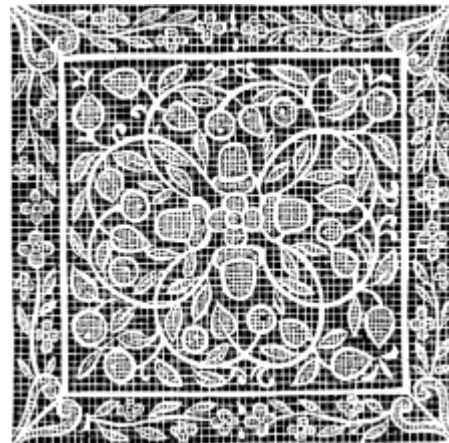
One of the first steps is simply to educate ourselves and others. Knowledge is a powerful tool, and it can drive the action needed to protect our communities and future generations.

- **The Power of Prevention:** Early screening for CMV and antibiotic-induced hearing loss is crucial. These steps can significantly reduce the number of children with permanent hearing impairment, and we can act on them now.
- **Evidence for Immediate Action:** Research shows that early detection of hearing loss leads to better outcomes, improving language and cognitive development. Early intervention reduces both individual and societal burdens.
- **The Emotional Weight:** The Summit went beyond data; it was about the real human lives affected. Pam Rogers’ heartfelt testimony

about her son Christopher’s journey highlighted the ongoing challenges of living with CMV. These personal experiences remind us of the urgent need for change and the tangible impact we can have when we prioritise prevention and early intervention.

Moving forward, we must build on this knowledge and push for meaningful actions that make hearing health a priority. This includes spreading awareness, influencing policy, and ensuring access to early detection and prevention services.

The work ahead is a collective mosaic of effort.



Every effort, whether it’s research, education, or community action, is a crucial piece that fits together to form a comprehensive solution to preventing hearing loss.

Rising Tides: How You Can Help

Making hearing health a national priority requires collective action. Whether you’re a policymaker, healthcare provider, or community member, there are several ways to make an impact:

- **Advocate for Change:** Promote the importance of ongoing hearing screenings for all children. Raising awareness is the first critical step in making hearing health a priority within healthcare policies.
- **Share What You've Learned:** Educate those around you about the risks of CMV and antibiotic-induced hearing loss. Personal conversations—both online and in person—can inspire others to take action.
- **Support Families:** Provide resources and guidance to families dealing with hearing challenges. Your assistance can make a significant, lasting difference in their lives, helping them navigate the journey with confidence.

As we work toward national change, **advocacy** and **awareness** are the pillars that will support our mission. Here are some next steps for effective advocacy:

- **Push for Policy Change:** Advocate for national policies that integrate ongoing hearing screenings and more responsible antibiotic management. A unified voice across sectors will make all the difference.
- **Public Education Campaigns:** Launch large-scale campaigns that raise awareness of CMV and antibiotic-induced hearing loss. These campaigns can educate the public, mobilise communities, and drive action on a larger scale.
- **Support Ongoing Research:** Fund studies on antibiotic-related hearing loss, early detection methods, and CMV prevention (e.g., vaccines, antivirals) to prevent hearing loss. Engage & involve consumers in the research.

Rising tides lift all boats.



When we work together, we create momentum for change. Every action, no matter how small, contributes to a larger tide that can improve the future for all children.

Turning the Tides: Protecting Future Generations

The National Deafness Sector Summit was a pivotal moment in the movement to make hearing health a national priority. It brought together experts, families, and advocates in a shared vision for change. This issue is not just about healthcare—it's about the future of our children and ensuring they have every opportunity to thrive, free from preventable hearing loss.

The time for national conversations on hearing health is now.

We can make a lasting impact and ensure that future generations are protected from preventable hearing impairments.

Together, we can turn the tide on preventable hearing loss. As a community, we can shift the course toward better awareness, prevention, and early intervention.

Recommendations

The following recommendations outline actionable steps for individuals, organisations, and communities to take ownership of. Through collaboration and partnerships, these steps provide a shared framework for stakeholders to work together in preventing hearing loss and protecting hearing health.

1. **Implement National Guidelines:** Advocate for nationwide, consistent screening for CMV and improved antibiotic management to prevent hearing loss. This includes using existing CMV guidelines and developing new guidelines for antibiotics.
2. **Expand Genetic Screening:** Ensure genetic screening for hearing loss is accessible to all children, while considering the potential for false positives and ethical concerns. Testing should be conducted responsibly, adhering to strong ethical standards, with informed consent and counselling to help families accurately interpret the results.
3. **Raise Public Awareness:** Launch campaigns to educate the public about the risks of CMV, antibiotic-induced hearing loss, and how they can take preventive action.
4. **Support Ongoing Research:** Fund research into the links between antibiotic use and hearing loss, CMV prevention (including vaccines and antivirals), and early detection methods for hearing loss.
5. **Empower People:** Equip women, parents, and caregivers with the knowledge to prevent CMV and make informed decisions about antibiotic use. Encourage proactive engagement with healthcare providers, asking informed questions about potential risks to hearing.

By focusing on these interconnected steps, we can build a society where hearing health is protected, early intervention is the norm, and no child's future is defined by preventable hearing loss.