Transcript

Deafness Forum Australia
Virtual National Deafness Sector Summit
Protecting Young Ears:
Navigating Disease and Medication Risks
(Via Microsoft Teams)

Friday, 15 November 2024 at 1pm

JANE LEE: Thank you all for joining us today as we relaunch our National Deafness Sector Summit as a series of meaningful conversations around hearing health and the relevance to deafness and hearing health communities.

My name is Jane Lee. I am the National Manager of Health Programs for Deafness Forum Australia. I'll be moderating today. I'm also joined by our team. So Hayley Stone, our Director of Disability and Advocacy, is helping to manage and moderate the chat. Also, our CEO, Steve Williamson, is here with us too.

Please feel free to drop a hello and introduce yourself in the chat. Please note this webinar will be recorded and available for public viewing.

Before we get started, Deafness Forum Australia is headquartered in Canberra. We would like to acknowledge the traditional custodians of this land, the Ngunnawal and Ngambri peoples. I pay our respects to their Elders past and present and any First Nations people joining us here today. Our work is nationwide and we recognise many of you are joining us from elsewhere and we pay our respects accordingly.

Just very quickly, Deafness Forum is the national peak body for Australians with hearing challenges, ear or balance disorders and their families and supporters. Our priority is to make hearing health and wellbeing a national priority. Some of our focuses are around rural and remote health, around culturally and linguistically diverse communities and of course children's and children's health.

NEW SPEAKER: Excuse me, Jane. A couple of people have indicated they're not hearing any sound, so I thought I'd just share that - on the chat.

JANE: Yes. You might want to possibly double check your sound settings. Can you put it into the chat and Hayley can try to help troubleshoot?

HAYLEY STONE: Very happy to help. Also, Kurt needs his screen on because he's the interpreter and Lee.

NEW SPEAKER: Yes, Jane, can you get Kurt and Lee on?

HAYLEY STONE: I can.

JANE: Yes. Thank you, everyone. As mentioned, this is the first time that we're doing this, so in some ways you're a little bit of a guinea pig, so we're

just working our way through things. Please be patient with us. We promise this will be a really great presentation for everyone.

So we're really pleased you can join us today. We hope you see today as an opportunity not just to learn from our speakers, but to engage in conversation. After all, great things come from great conversations and we encourage you to engage. We really only have one rule. Please stay curious, ask questions, share insights, comments.

Our topic today is "Protecting Young Ears: Navigating Disease and Medication Risks". We have two presentations for you today, one on antibiotics and then one on - I'm just going to say CMV because I'm not going to be able to pronounce it very well. Then we'll have a Q&A session.
If you have any questions for our speakers, please submit them in the Q&A tab. Any other comments, please use the chat and we really hope that you enjoy our presentations today.

So I'm just going to quickly introduce you to our first speaker. To begin our summit, we're really excited to hear from Dr Duaa Gaafar. She's a general paediatrician at the Royal Children's Hospital and an Honorary Research Fellow at the Murdoch Children's Research Institute. Her expertise is in paediatric clinical pharmacology, particularly in the areas of adverse drug reactions, drug allergies and pharmacogenetics, so she's an invaluable voice to the field. Today she'll be sharing her current work into the impacts of antibiotics on hearing loss in children. Please join me in welcoming Dr Duaa Gaafar.

DR DUAA GAAFAR: Thank you, Jane, and thank you, Deafness Forum Australia, for the chance to speak today. I will start by sharing my presentation. Okay.

So thanks for the presentation. I'm Duaa, one of the paediatricians at the Children's, and I do a lot of work in clinical pharmacology and I have a PhD in clinical pharmacology and today I'm going to be talking about the antibiotics and hearing loss in children. These are the things that we're going to go through today and without further delay, let's get started.

So we know that hearing loss is one of the most common sensory disabilities worldwide. It affects around 34 million children, according to the WHO. As a paediatrician, early onset hearing loss does have major effects on children's development.

We know that the cost of lifelong deafness has been reported in America to be

about $300,000 US per patient and that means if we can prevent that, that would be great, and antibiotics-induced ototoxicity is potentially preventable. So in patients who have received treatment for a disease called tuberculosis, the studies have shown that about 40% of them who developed hearing loss could have been prevented. And there are many antibiotics that could cause this, but today I'll be focusing on two important antibiotics, vancomycin and aminoglycosides, which is a group of antibiotics that includes many antibiotics like gentamicin, tobramycin and amikacin. As you can see from this graph, in Australia among the 20 most common antimicrobials being used, the vancomycin and gentamicin come in the top 20.

These antibiotics do cause hearing loss, so what we know is that among the glycosides group we know that it can cause irreversible hearing loss and the incidence has been reported to be about 40%, while vancomycin, despite being reported as reversible, there are more cases of reversible hearing loss and the incidence overall is reported to be about 8%. However, it's higher in children.

Despite these figures, there are no national guidelines regarding hearing screening for antibiotic use or prolonged antibiotic use. We know that Queensland Health, for example, has a targeted surveillance program for high-risk children, but antibiotic use is not one of these particular criteria.

So how does aminoglycoside cause this ototoxicity? Simply it just damages your hair cells, which means you're not going to be able to hear again, and we know that with this damage, it's usually severe and profound hearing loss and it's irreversible.

There are many risk factors. Some are related to the medication itself, related to the dose, the duration of the antibiotic and use of other medication that can cause hearing problems, as well as some genetic susceptibility, which I will talk about further.

For the vancomycin, we don't completely understand the mechanism how it causes hearing loss. However, it's thought that it can cause direct nerve damage. It usually causes high-frequency sensorineural hearing loss and the spectrum is from transient to permanent hearing damage.

When it comes to risk factors, again, it's related to the dose, the duration, but also there are other factors, like renal function because this medication gets cleared by your kidneys; your age; and the medication level in the blood, which is the high trough levels.

We also know that in children the incidence is possibly a bit higher. So studies have shown that in neonates receiving vancomycin, 22% of them in comparison to 7% of these babies who were in special care and didn't receive vancomycin might fail their primary hearing screen and might actually develop hearing impairment. The German Neonatal Network data links vancomycin dose into the abnormal hearing in children up to the age of 5 and that hearing damage can happen any time between 2 to 5 weeks after vancomycin exposure.

So what do we do, how can we prevent this? I think there are many prevention strategies that have been identified and I'm going to talk about a couple in more detail, but one of them is identifying high-risk populations and where the questions come is regarding if the genetic screening has a role, then minimising exposure, given the dose and the duration of the medication has come up a couple of times related to development of hearing loss, and then also making sure that we do preexposure audiometric testing, having baseline hearing tests for those people who are at high risk of developing the hearing loss with prolonged antibiotic use. So we'll talk about genetic screening as well as the dosing.

So to start with, genetic screening, the question is does carrying certain genetic variants increase your risk of developing hearing loss after exposure to aminoglycoside, and to answer this question, this was part of my PhD work doing a systematic review to look at what evidence is there. We know that hearing loss in aminoglycoside has developed in patients in this study between a few days to months, but sometimes up to years after exposure to the antibiotic aminoglycoside.

There are many variants that have been identified. However, the top two are the ones that have the strongest evidence and some of you might have heard of that mitochondrial 1555 AG. Strikingly in this particular variant, the studies have shown that patients who were exposed to the antibiotic, in 63 up to 100% of them they ended up developing hearing loss, but also found that up to 40% of those who carried the variant have developed hearing loss despite not receiving the antibiotic. The second variant, the 1494 CT has lower prevalence, but also has shown that exposure to antibiotics, aminoglycoside in particular, increases your risk of developing hearing impairment.

However, these studies come with some risk of bias as well as many limitations. None of these studies actually evaluated the cumulative dose or the concentration of the medication or compared what does it mean carrying the variant versus not carrying the variant and receiving antibiotics.

So to put this into clinical practice and what implication does this have? There are many pros of knowing if you carry these genetic variants. Potentially, we could prevent hearing loss and it could help to inform the treating decisions. However, there are also many cons. So there are possibility of false positive results. If you have the variant and decided to use alternative antibiotics, that can increase the risk of drug resistance. If you got a negative result, that does not eliminate the risk of developing hearing loss, and we don't have enough data about the cost versus benefits. So more research is certainly needed in this area and careful consideration of interpreting the results.

The second point that I want to talk about today is the therapeutic drug monitoring and model informed precision dosing and that's because it came up a couple of times that the medication concentration can be linked to the development of hearing loss. In the modern era, there is more move towards beyond the traditional therapeutic drug monitoring, which is just a drug concentration, into integrating the mathematical prediction of the dosing through what's called the MIPD, or the model informed precision dosing, because that takes not only the dose of the antibiotic, but takes into consideration the patient's age, patient weight, dosing history, the levels in bloods, including your kidney function as well as the medication level before it gives you the right dose that you would need to reduce the risk of side-effects, including hearing loss.

There's been many studies that looked at this and the effect of it in preventing side-effects. So, for example, when it comes to aminoglycosides, we know that the MIPD based dosing has significantly reduced hospital length and stay, nephrotoxicity, which is the kidney problem immediately related to doses, and overall health cost has been published this year by Minichmayr and his group.

Also, at the Children's Hospital we've done a prospective multi-centred trial to evaluate MIPD in vancomycin in neonates and little children and we found that using these calculators, which you have the logo for, which is KidsCalc, has resulted in 75% and 83% of achieving target concentration without having many side-effects.

So the take-home messages to try to prevent hearing loss related to antibiotics is that there is more evidence that individualised model-based dosing to reach target levels is essential for minimising ototoxicity and hearing loss as well as that certain mitochondrial variants can increase your susceptibility of aminoglycoside-induced ototoxicity. However, further research is needed in this area.

Before I finish, I would like to acknowledge the MCRI Antimicrobial Research Group that I'm part of and a special thanks to Amanda Gwee and Amanda Wilkins because they've done lots of work related to the MIPD and they've helped develop the Vanc calculator. And another thank you for Deafness Forum Australia and I'll be looking forward to all your questions in the Q&A session. Thank you.

JANE LEE: Thank you, Duaa, for that insightful presentation. If you do have any questions, please drop it into the Q&A option at the top and we can answer questions at the end.

So our second presentation is going to be on congenital cytomegalovirus, CMV, prevention. So we've got a team of presenters for this one. We have the pleasure of hearing from Associate Professor Hayley Smithers-Sheedy. She's a Principal Research Fellow at the Cerebral Palsy Alliance Research Institute and the University of Sydney. Her work is at the intersection of cerebral palsy and congenital infections. This has been pivotal, particularly in her research on the prevention of cCMV, which can lead to significant neurodevelopmental disabilities. She will share insights, opportunities for preventing cCMV, a topic that holds great promise for improving the lives of many children. Please join me in welcoming Associate Professor Hayley Smithers-Sheedy.

Also joining her is Kath Swinburn. Kath Swinburn is the Research Officer and Ethics Governance Manager at the Cerebral Palsy Alliance Research Institute and she's passionate about involving people with lived experience in research and co-leads CP Quest. It's a wonderful initiative that ensures the voices of those impacted by cerebral palsy are central to the research process. She also leads several key projects aimed at preventing CMV and we're so grateful to have her here to share her work. Please welcome Kath Swinburn.

And lastly, rounding up our team of presenters is Pam Rogers. She's a passionate disability advocate and a devoted mother of Christopher, whose personal journey and commitment to supporting other parents is truly inspiring. Pam holds qualifications in early education and is currently training to be a doula. Her expertise as a parent peer facilitator and her work in cCMV research has empowered families navigating the complexities of raising children with disabilities. She's also a member of CP Quest and a research partner across a range of cCMV studies. We're really happy to have Pam here to share her insights and her lived experience with us today. Please give a warm welcome to Pam and then I'll turn over to the CMV team. Thank you.

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: Fantastic. Thanks so much, Jane, and also just to ask whether Pam, can we make sure that she has her video and microphone, that she can access that when it comes to her turn to speak. That would be wonderful if you could help us with that.

Okay, I'll just share the slides. Okay, so can everyone see that? Oh, actually, I'm just going to do that again. Okay. So I again wanted to say thank you to Deafness Forum Australia for having us along today. I think with that very lovely introduction I won't introduce myself again, but just to say I'm very glad to be here with Kath Swinburn and also the CMV advocate extraordinaire Mrs Pam Rogers.

We're here to talk to you today about a little known virus called cytomegalovirus, or CMV, which is a common cause of sensorineural hearing loss, cerebral palsy and other neurodevelopmental disabilities.

I'd just like to acknowledge the traditional owners of the land we meet on today and all First Nations people with connection to this land. I pay my respects to the Elders past, present and emerging for they hold the memories, the traditions and the culture of the Aboriginal and Torres Strait Islander people across the nation. I'm talking to you today from Gayemagal land and Garigal land in Sydney's Northern Beaches and you might like to share in the chat or in the Q&A the country that you're dialling in from. And I wanted to highlight this beautiful artwork that our colleague Tan Martin, who is an Aboriginal midwife living near Dubbo, painted for us and which has been included in the congenital CMV information pamphlets that you'll hear about later on today.

Before we continue, I just wanted to acknowledge how appreciative we are to be working with these and other wonderful collaborators in Australia and internationally. A big shoutout to Valerie Sung, who has lead the way for much of the hearing and deafness research in this space. We're also really grateful to Lisa Hui, Natalia Rode and Antonia Shand for all their support and leadership in the maternal CMV space.

So just to let you know where we're coming from in our little team, we endeavour within our team to ensure our work reflects the priorities and wishes of people with lived experience of cerebral palsy. So this approach is somewhat in the DNA of our organisation, which was founded in 1945 by Neil and Audrie McLeod, who had a daughter with cerebral palsy whose name was Jennifer. To this day, our organisation that they built continues to be led and guided by families. Similarly, when our research institute was established in

2005, a Delphi study was completed by our colleagues to identify the research priorities of families so that we could ensure that our work was focused on these priority areas.

Interestingly, reducing the incidence and severity of cerebral palsy and associated impairments was highlighted as a key priority by families. This is so important because the theme of today's symposium is, of course, prevention. We wanted to share with you now a short video from a wonderful parent called Bree who's going to share her family's experiences of congenital CMV with you. This video was made for a midwives course that you'll hear about later. I'm just hoping it will play nicely for you. (Video played):

BREE PENNIE: I want to tell you about our son Dax, our CMV warrior. Dax was born with congenital cytomegalovirus, or CMV. I'd like to share with you the impact that CMV has had on our lives.
Dax was born healthy, only to fail his newborn hearing test at just a few days old. This is the moment when our lives that we knew and had hoped for were turned upside down. It took three and a half months to get the official diagnosis of congenital CMV and the kicks in the guts just kept on coming, diagnosis after diagnosis.
As a result of the CMV, Dax has unilateral hearing loss, a cortical vision impairment, microcephaly, brain changes including polymicrogyria, quadriplegic dystonic cerebral palsy, epilepsy and a global development delay.
Our initial reaction was disbelief. No one I knew had heard of CMV, not my family nor my friends. This was followed by guilt on my part. How could I unknowingly carry a virus which was attacking my unborn child? This soon led to anger. Why hadn't anyone told me the risks of CMV?
Congenital CMV has tested our relationship. It has challenged us, but we have grown stronger, but not without the emotional toll, the physical strain and the financial pressure.
Dax is a little legend. He has a smile that will melt your heart, a laugh that is infectious and determination that will move a mountain. I'm optimistic about Dax's future. He has come so far. He has been given every opportunity to thrive.
One of the important messages you will hear in this course is about the simple hygiene precautions that pregnant women can take to reduce their chance of contracting CMV. Now that I know what I could have done, I'll be sure to tell all my family and friends and anyone who will listen.

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: Okay. So you can see why we're here today talking about CMV. We have families who really want this message about CMV spoken about and opportunities for prevention explored.

So what is CMV? It's a common herpes virus. It's endemic in our community. About 50% of us will have had the virus by the time we're young adults and it's transmitted through close person-to-person contact with bodily fluids like saliva and urine.

Most people with CMV infection will be asymptomatic, so they won't know that they've picked up the virus, or they might have a mild flu-like illness. However, CMV can cause problems for two specific groups, those who are immunocompromised and pregnant women.

CMV is common in young children, who can easily transmit CMV to each other as they can shed the virus in their urine and saliva for up to two years after infection, and you can see the lovely babies on this slide here and see how well babies can share saliva with each other and their parents. So this is where young mums can pick up CMV infection.
So we know that people who work with or care for young children are at an increased risk of infection.

So congenital CMV usually occurs when this virus crosses the placenta and infects the developing foetus. Most babies born with congenital CMV will remain well. However, a small proportion will experience long-term neurodevelopmental disabilities, including sensorineural hearing loss, vision loss, intellectual impairment, CP, seizures, and in some cases, congenital CMV can result in stillbirth and neonatal death.

In terms of hearing loss, congenital CMV infection is the leading non-genetic cause of sensorineural hearing loss worldwide. In fact, 20 to 30% of all sensorineural hearing loss in young children is due to congenital CMV and around half the children who have signs of CMV in the neonatal period will go on to have unilateral or bilateral sensorineural hearing loss.

This hearing loss that is associated with CMV is usually progressive and/or late onset and it's understood to be a result of the ongoing inflammatory response to the infection. Fluctuating hearing loss in one or both ears is also common and this means that around 10 to 20% of babies born with congenital CMV will have normal hearing at birth, but will go on to develop hearing loss over time. Even up to 5 years of age there can be this progressive pattern. This makes it quite difficult to identify all children through the newborn hearing screening pathway. It really highlights the importance of the ongoing monitoring of hearing for children born with CMV.

Congenital CMV is much more common than you might realise. In fact, it's the most common infectious cause of disabilities in babies in Australia, far more common than other conditions that are well known and that we routinely counsel pregnant women about during pregnancy. So we tell people about toxoplasmosis and listeriosis and rubella, and happily we now have an excellent vaccine for rubella, but CMV causes one baby born every day with lifelong disabilities due to this virus.

So it's very exciting to see that over the last decade or so we have had an expansion of opportunities for prevention of congenital CMV. This is a figure that our colleague from the University of Melbourne Lisa Hui published that we really like and I'll walk you through it now.

So firstly, we have primary prevention, which would be in the form of a vaccine for women planning a pregnancy. There's some real promise in this area, with a trial of some new mRNA vaccines, one of which is being trialled internationally in a project called CMVictory and there are 13 recruitment sites across Australia for this trial. We still have to wait some time for the results of this and probably future trials, but this is an exciting space to watch.

The next prevention opportunity lies with hygiene precautions during pregnancy and my wonderful colleague Kath will talk to you about this some more, but we know that hygiene precautions are effective in reducing the risk of CMV in pregnancy.

In terms of secondary prevention, randomised control trials have in recent years highlighted the effectiveness of antiviral medications such as Valacyclovir for reducing the rate of foetal cytomegalovirus infection after maternal primary infection in early pregnancy. So this has raised the question as to whether we should now be thinking about screening pregnant women for CMV.

In terms of tertiary prevention, there are now a number of studies which have shown that Valganciclovir given early to infants with symptomatic congenital CMV can substantially improve hearing and developmental outcomes. But this is an antiviral that has some toxicity associated with it and it's currently recommended for use in children who have significant signs or symptoms of CMV in the neonatal period. However, prescribing practices differ across specialists and regions and we're hoping that some work we're doing with the CMV register will tell us more about the use of these antivirals.

So as you can see, this is an exciting prevention space to be in and to talk more now about primary prevention, I'll pass over to Kath.

KATH SWINBURN: Thank you so much, Hayley, and thank you for driving the slides for me as well.

Hi, everyone. So as Hayley mentioned just earlier, we know that following simple hygiene strategies during and just before a pregnancy can be effective in reducing the risks of CMV infection and recently - I'll tell you more about this in a moment - we have been running a media campaign looking at advertising these hygiene precautions, Wash with Care, Kiss with Care and Don't Share. So avoiding contact with saliva and urine, particularly from young children, is the key here, so obvious examples like washing your hands carefully after changing nappies, avoiding slobbery kisses on the mouth from toddlers whilst you're pregnant, and not sharing food, cups and cutlery with young children.

Further on the topic of primary prevention, just over on the next slide, please, Hayley, we also now have clear recommendations, professional recommendations, in the form of guidelines and statements. So in 2017 we had the international CMV consensus statement being released, a really important international recommendation around the prevention of CMV.

RANZCOG - that's the Royal Australian and New Zealand College of Obstetricians and Gynaecologists - they released some guidelines in 2019 which were updated just last year that made similar recommendations around preventing CMV and hot off the press, very recently in the Lancet we saw some new consensus recommendations being released from Europe. What's important about all of these guidelines is that they provide a really clear unequivocal recommendation that all pregnant women and families planning a pregnancy should be provided with information about CMV and the prevention strategies that we know can be effective in reducing the risk.

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 10% of maternity health professionals in Australia routinely report that they discuss CMV prevention with pregnant women and families in their care.

Maternity professionals have also reported in the research some barriers to discussing CMV with pregnant women in their care. So a large collaborative team that Hayley mentioned earlier from around Australia, we have worked together with people with lived experience of CMV - Pam Rogers, who you'll meet soon, being one of those people - to develop a suite of information

resources for families and for health professionals about CMV, about the risks and about how you can best protect yourself during pregnancy.

So this is - we've got pamphlets and brochures in English and multiple community languages. We have posters that could be placed in waiting rooms or in clinics and Lisa Hui, our colleague in Melbourne, also develops, on the far right of your screen now, some really excellent handouts for women who have been diagnosed with CMV during a pregnancy and what they can expect to happen.

These are all freely available on the Cerebral Palsy Alliance website. You can see the link there on your screen, or the QR code. So they can be downloaded free, but also at that QR code you can order multiple copies to be posted to your clinic or your hospital free of charge to give to patients. Thanks, Hayley.

So also in response to maternity health professionals reporting that they didn't feel confident, they didn't feel comfortable speaking about CMV to pregnant families, our team also has been busy developing a series of e-learning courses, one specifically for midwives, one for GPs, and most recently one for obstetricians and gynaecologists. All of these education modules are freely available and the beauty of the e-learning course I think is that they're available nationally and all have been accredited with the relevant professional bodies, such as Australian College of Midwives, the RACGP and RANZCOG and the courses provide practical relevant information about CMV, about how to counsel pregnant women and families and about where to find resources.

We have evaluated the course for midwives and the course for GPs - they're the first two that we released - and the evaluation showed that the courses significantly improved knowledge and confidence among these health professionals to counsel pregnant women and families about CMV. Thousands of midwives and GPs have now enrolled to do the course nationally and the course for obstetricians and gynaecologists has just been released so I guess we'll keep you posted about that.

As a part of the primary prevention campaign that I spoke about a little while ago, we have also been running a social media campaign. So we do this year round and then I guess we really ramp this campaign up during June of every year, which is CMV Awareness Month. So we use a range of social media platforms, the ones that you would all know about, Facebook, Instagram, YouTube and catch up TV, and the campaign aims to raise awareness about CMV among our target group of pregnant women and families. Last year we even ventured into new ground, which was partnering with an influencer

group, so a paid partnership with Kindred, which is a large information portal for pregnant women and families with young children, and as I said, in addition to this, every June we run a paid media campaign and we target TV, radio and major print news. You can see on screen now some of the things that we've done, radio and articles in major print news.

The other thing, we got donated some air time through Nova FM and Smooth FM and we developed some 30 second radio ads, which was something new for us. So we'll try to play you one of them now. (Radio ad played):

Have you thought of any names yet?
No. There's so much to think about, hospitals, what foods to avoid.
Mmm, true,and you know about CMV right?
CMV. What's that?
Oh, it's a common virus my midwife mentioned. If you get it during pregnancy, it can cause lifelong disabilities in some babies.
How can I protect myself?
Don't worry, it's simple. Just make sure you wash hands after nappy changes and don't share food or drinks with young kids.

To learn more, search "reduce your risk of CMV."

KATH SWINBURN: Thanks, Hayley. And finally, I just wanted to share a few interesting pieces of CMV-related research that are in progress at the moment and obviously to say this is just a few. There's lots of research, fabulous research, going on at the moment in lots of different spaces that Hayley was talking about before, so primary prevention as well as in the area of I guess maternal CMV and neonatal CMV. So I'm just touching on a couple today.

The first I wanted to mention is a Delphi study that we'll be doing early next year. So a Delphi study is a CMV research priority setting study, for those of you who haven't heard of a Delphi study before. It involves surveying clinicians, researchers, public health experts and, importantly, families and people who have been impacted by CMV and the survey is asking them what they believe is the most important CMV research priorities that we should be looking at.

So the outcome hopefully of the research is an agreed upon ranked list of CMV research priorities, starting with the most important, to help guide all of us as to where perhaps we should be looking for funding and where we should be spending our valuable resources on research. So that hopefully - keep your eyes peeled for that. About March next year hopefully that will be coming out.

Some other important studies are the ESE-CMV study, which our colleague Lisa Hui in Melbourne is heading up. She's investigating different models of maternal CMV screening and GPs' readiness to screen women.

Hayley touched on earlier the CMV register that she is working hard on along with Valerie Sung in Victoria. This is a new register, fairly new, that's been set up, as Hayley said, to help us understand some of the long-term impacts of congenital CMV and the use of the antiviral therapies that Hayley spoke about. And then of course there's the CMVictory trial, so the vaccine trial that a lot of us are really watching with interest to find out what the results of that would be.

So now hopefully, if we can get Pam Rogers, if she has the ability to turn her camera and sound on - I'd really love to hand over to Pam, who is our amazing CMV research partner, a mother and disability advocate. Pam has bravely volunteered to come today and share her family's experience of CMV with us, so thank you so much, Pam.

PAM ROGERS: Thank you. So I've been invited here today to share a family's perspective and while I cannot speak for all, I'll share our personal journey, our family's unique circumstances, our experiences from the start, and the impact CMV has had on our boy and the flow-on effects of this horrendous virus. I warn you, I am a crier, so apologies in advance.

Tom and I had only been together for six months when we found out we were almost 12 weeks pregnant. It took a hot moment for us to process, make a decision and commit to each other and our baby, but we were soon excitedly preparing for our life together, sharing our news with extended families and friends. We were young, naive and in love, blissfully unaware of the true weight of the trajectory we'd just set our life on.

Around 15 weeks I went to the doctor complaining of a headache and exhaustion, nothing too significant or notable, but enough to have me feeling pretty crappy. I was given a week off work to rest. I was told that growing a human is hard work, I needed to take it easy and be kind to myself. After some healing rest and a few days sitting with and processing the epic life changes and sudden shift in our priorities, I returned to work, feeling great and we continued on, planning and growing more excited and more in love each day.

A routine midwife appointment at 26 weeks found my belly measuring small.

At only 19 centimetres, we were sent up to the hospital for scans and monitoring. A follow-up scan two weeks later was not so routine or easy-going. They found enlarged ventricles in his brain and his growth was restricted. We were referred to the foetal medicine unit at the Canberra Hospital, scheduled for regular scans and monitoring, had bloods drawn, planned an amniocentesis and booked a foetal MRI.

By chance, the timing of everything saw us pop down the coast for the annual family weekend that Tom's large, loving and large extended family hold each year. We were embraced in a space of love, support and connection and while we were worried, we had no idea the depth of heartache and devastation that was ahead.

On our way home, on Monday, 10 February, we received a call from the FMU asking us to come in to discuss the results of our scans and tests. Late that morning, in the FMU family room, at 31 weeks pregnant, we were offered termination. It was made clear that the results of all of the tests and scans all pointed to his brain being underdeveloped and misshapen and that he was not compatible with life.

The word was barely out of our doctor's mouth before Tom and I were shaking our heads. If our baby was not long for this world, we were not going to force nature's hand. He was given the diagnosis of neuronal migration disorder and it was speculated that the cause of this was CMV.

Over the following weeks, we made countless visits to the FMU, regular scans to monitor baby, each one revealing another way his organs and overall growth and development was being compromised. We met with doctors, midwives, social workers and counsellors to plan for the delivery and prepare us for the expected outcome. Our goal was to deliver and cuddle him before he died, to be gifted the grace to love him fiercely, holding on to the few moments we were granted, however limited they were. But it was repeatedly made clear that this was unexpected, that the interruption to his growth and development was so severe that he would not survive delivery.

On Friday, 28 March, at 37 and 5 weeks, nature did its thing. I went into labour and our gorgeous boy Christopher Phillip was born, alive, tiny - compromised, but alive. Congenital cytomegalovirus was confirmed two days later. Over the following days, they scanned, tested, examined, screened, poked, pricked and prodded our boy.

The days turned into weeks. The screening, testing, scanning, examining,

poking, pricking and prodding continued. We learnt that during pregnancy the virus had crossed the placenta and affected his liver, his kidneys, spleen, heart, lungs, bone marrow, eyes, ears and most severely his brain. We spent every waking hour at the NICU by his crib showering him with our love and the love of our extended family.

Late every night we made the gut-wrenching trip home to our little unit in Queanbeyan where we lay restless and hardly sleeping waiting for it to be an acceptable time to return to his bedside. Miraculously, we were sent home just three weeks later with the cytotoxic medication valganciclovir, a list of referrals, a pile of paperwork, a teeny tiny baby and absolutely no idea what we were doing. Doctors were unable to give us an accurate prognosis. "Take him home and love him while you still can", they said, and so we did and we haven't stopped.

Over the next 18 to 24 months, we received a host of secondary diagnoses - microcephaly, severe global developmental delay, spastic dystonic quadriplegic cerebral palsy, epilepsy, cortical vision impairment and unilateral hearing loss. The hip dysplasia and residual constipation would come later. But in between specialist appointments, check-ups with the paediatricians, follow-ups with genetics and infectious diseases, hearing and vision assessments, hospital admissions and running all over Canberra and Sydney to every different kind of therapy and early intervention available, we were on an epic journey of love.

Our boy has opened our eyes to the beauty in this world and despite how deeply it hurt each and every time a new diagnosis was handed down, a hospital admission threatened his very existence or a new assessment rubbed in our faces all of the things our boy couldn't and would probably never do, the love and light that we shared with him ran deeper and it always won.

In 2016, we made the big decision to give him a sibling and what a perfect breath of fresh air was our little Charlotte, the most incredible girl who looked upon her older brother with such adoration and she still does today. Watching them together is pure magic and clearly bewitched us because we went on to grow our family by two more incredible little people, first Matilda in 2018 and finally Maxwell in 2021. All three of them share the most beautiful and unique bond with Christopher and we could not be prouder of the way they love upon and care for one another.

In 2018, at almost 4 years old, after nine months with an NG tube, he underwent surgery for a PEG so that we could continue to nourish him. Later that same year, when our Matilda was only 6 weeks old, he endured a bilateral

femoral osteotomy to relocate his hips. The recovery was long and awful for all of us, but his courage and determination shone and he was once again able to thrive.
He has since undergone another two hip surgeries and in 2019 he underwent an appendicostomy to relieve his residual constipation.

Christopher is now 10. He is non-verbal, non-mobile, tube fed, and relies on us for everything. He's on 12 different medications to manage his pain, tone, spasticity, seizures and reflex. He has multiple seizures a day, both absent and gelastic. Our day-to-day routine sees us administering medication four times a day and setting up his feeding pump for feeds four times a day, both via his PEG, ensuring that he is moved regularly to prevent pressure sores, flushing his bowels via the appendicostomy, getting him to various therapy appointments and allowing him to engage with life.

He has splints, AFOs, braces, a wheelchair, a standing frame, supportive seating, a hoist, a commode for toileting and showering and a specialised bed. He attends a specialist school. We have modified a car and have made modifications to our home.

He is also cheeky and loving and funny and smart and kind and full of joy. He's a typical 10-year-old boy who enjoys school and hanging with his friends. He loves swimming and music. He equal parts loves and is annoyed by his siblings. His favourite colour is green, he thinks playing tricks on people is the funniest thing out, and hanging at home on the weekend surrounded by our extended family and friends is his idea of a good time. He has eyes that pierce your soul and the most amazing smile that can brighten the darkest of days.

I wish I could say that our story was unique and that it was a standalone experience, but the fact that we're all here today shouts from the rooftops just how far from the truth that is. I don't need to tell you that the outcomes of cCMV range from mild hearing loss to stillbirth and the effects are often devastating and unexpected, rippling out to impact entire families, so why aren't we doing more?

I know that it takes time, resources and education to bring about change, but we're talking about a virus that was discovered the same time as the measles, that is the leading viral cause for disability in children, that impacts 2,000 births each year in Australia, 400 of which will have lifelong disabilities. It's ludicrous that we're not talking to women about this.

Learning that CMV is a common virus with its effects known and well

documented was a kick in the side while we were down. The experience of holding our breath at each scan not knowing if his heart would still be beating or labouring to deliver him into this world not knowing if he would breathe or stay with us forever has shaped us into the resilient parents we are today.

Families have shared over and over again that letting the knowledge sink in that there is education and prevention action available to expectant mothers, but not shared freely with them, amplifies their trauma and adds to their guilt. If we had access to the information and knowledge when we first found out we were pregnant with Christopher, would our lives be different today? Could my choices and attention to prevention action have made a difference? It may not have, but I wasn't given a chance to try, so we will never know.

Prevention action needs to be common knowledge and common practice, just like avoiding kitty litter and not eating soft cheese. Doctors and midwives need to be well versed in educating and supporting expecting mothers. Research into prevention, treatment and outcomes needs to be continued, funded and supported. Women need to be empowered to make informed choices with knowledge, education and information easily accessible.

Without CMV, would I still have a beautiful boy who loves his mum? I have no doubt. Would he still like swimming and music? Probably. Would his favourite colour still be green? Who knows. But what I do know is that without CMV, our beautiful boy would not have taught us the lessons in grace, humility, gratitude and love that we have learnt along the way. His presence in my life has opened my eyes to a world of diversity, inclusion, variety, alternatives and adaptations. It's made the colours more vibrant, the friendships more meaningful, the experiences more intentional, the compassion and understanding more free flowing and our hearts more full. Our gratitude is greater and our love is fiercer.

Being Christopher's mum has changed me for the better. I love my son and I wouldn't change a thing about him, but I wouldn't wish our journey and experiences on anyone. There are already some incredible people working tirelessly and dedicating their lives to the research and prevention of CMV, campaigning to raise awareness and spreading the word. Will you join them?

JANE LEE: Thank you, Pam. It's a real privilege to hear your story and thanks to all the presenters for all of their presentations.

We now have the opportunity to have a bit of Q&A panel session with all of the speakers and presenters. There have been a few questions that have come

through already. If there are any other questions that folks would like to ask, take the opportunity to engage with our speakers today, please put them into the Q&A section.

NEW SPEAKER: Thank you, it was amazing.

JANE LEE: Again, general comments, please put them into the comments, but questions, please put them in the Q&A, thank you.

So let's have a bit of the Q&A session. So first of all I think I'll talk to Duaa. Duaa, you talked a little bit about more research being needed. What do you think are some of the common challenges about researching research between antibiotics and hearing loss?

DR DUAA GAAFAR: I guess it depends on which part we're talking about. So if we're talking about the genetic variant, the first issue is how common are they. So we know that, for example, the most common one, which is the 1555 AG, is reported to be - has an incidence of 1 in 500. However, most of the work that was done on it, and there's actually more work, was done around the Asian countries. Luckily, Australia is very multicultural, so we actually don't know if the incidence in Australia is similar or not, but there is a current national project that is run at the VCGS Baby Star which hopefully will give us a bit more information around the incidence of these variants because if we don't know how prevalent they are in the community, then it will be very hard to justify testing everyone in the community. So that's sort of the first point.

The second point when it comes is that most of the studies are retrospective studies and none of the studies actually compared what does it mean to carry the mitochondrial variant. Is it a single dose of the antibiotic that can cause hearing loss, is it multiple doses, is it the drug level that you are too sensitive? So we actually don't know all this information.

JANE LEE: Thank you. Hayley, you did touch on this in your presentation, but what do you think has been the most effective strategies for raising awareness and educating healthcare providers and women about CMV?

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: I wish I knew the answer in terms of I wish I knew that there was just a magic thing that we do more of.

I think it's a steady plodding effort, to be honest, to do like a multi-pronged attack, if you would, in terms of the public health messaging. So we've done - we've listened to the health professionals who say they need some support

around counselling, et cetera, so we have the e-learning modules going for that group and providing free information pamphlets and posters and all the rest of it. And then we know that pregnant women get a lot of their information from social media, so we're attacking that level as well through all sorts of things that Kath talked around in terms of Facebook and Instagram and things that we never thought we would be doing as researchers, and we do - we have had increased interest and contact on our website, et cetera, so, you know, we are getting momentum.

Anecdotally, we get requests for information pamphlets from clinics all around Australia now. We've sent out thousands and thousands of resources, and we're happy to do, happy to keep doing. So it feels like we're getting some momentum, but to be honest, it feels like we've got a fair way to go and we're after anyone who would like to help and has any great ideas about how to amplify that messages more.

JANE LEE: Thank you. Kath, what do you recommend to - I think it's really important to have more lived experience involved in research. What do you recommend toencourage involving consumers in research and getting researchers to work with consumers? Have we lost Kath?

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: I think we lost Kath. I'll speak to it until Kath comes back on. So Kath Swinburn heads up a program called CP Quest, which is something that Cerebral Palsy Alliance runs and Pam is a member of, she's a CP Quest partner, and this is a group where researchers can come and put forward that they're doing a piece of research and the research they're doing is shared with members of CP Quest and families can put their hands up to say, "I'd like to be involved in that research".

Basically the thing that we've learnt most from people with lived experience and research partners like Pam is that most people want to be involved in research from the very beginning, like not brought in halfway through the project, they want to be involved from the very beginning to help sort of guide what research questions even are being considered and then all the way through to how their results are being interpreted, and they might come in and out of that process, but this holistic experience of the research I think is something that people want.

The other thing that we're really strong on is that people should be provided with some funding to acknowledge the great expertise that they're bringing. So, you know, wherever possible, people should be paid an hourly rate to help with research, just as we would with any other person with expertise.

I don't know, Pam, if you want to comment, but you're involved with a number of research studies and making sure we don't stuff up our consent information forms and all sorts of other things. I don't know if you want to talk to that.

JANE LEE: Yes. Would you like to comment at all, Pam, or is there anything that we can do to really help empower women and consumers?

PAM ROGERS: I think the big thing for me and a lot of the messaging that I get from a lot of other women who have had the similar experience is that we've kind of felt a bit disempowered because there was no information shared. So I feel really strongly about being involved with all of the research and trying to get the word out there as a way to kind of honour Christopher as one, but also because I'm huge on empowering women and we can't make informed choices if we don't have the information. So the more we can get the word out there and the more research we can be involved in to share our lived experience with researchers like Hayley and Kath to try to really prioritise what it is that families want, then that's only a good thing as far as I'm concerned. And I get to work with some really, really cool people.

JANE LEE: Thank you. Duaa, can you discuss the requirements and potential process for developing national guidelines for screening for antibiotic usage for children to prevent or minimise hearing loss and in what way could Deafness Forum support or any organisation support?

DR DUAA GAAFAR: That's a great question. I think perhaps it would be good to start with a group of - I'll talk about children, with a group of children that are at the highest risk, which I'll be able to identify possibly two groups, those children who have cystic fibrosis because these are - or respiratory condition because these are children that get lots of antibiotic courses throughout their life for chest tumour, and the neonates.

The newborn - neonates in neonatal intensive care units has lots of good guidelines and they don't particularly specify antibiotics, but if you look at - because they have many other risk factors and unfortunately, most of these babies who graduate from NICU end up being on antibiotics and that's when they get screened, but it would be good to identify or add antibiotic use, especially the high-risk antibiotics, in the guidelines.

For the other cohort, the CF, unfortunately there are no national guidelines in Australia to say that they have to get hearing screening, despite the fact that we know that they get lots and lots of antibiotics, including the

aminoglycosides. Overseas I know that in the UK annual hearing screening is part of the consensus and the guidelines here and that would be one good thing or one good place to start at if we were to advocate for hearing screening among the high-risk group.

JANE LEE: Thank you. To the CMV team, is vaccination available for women if they find that they're pregnant - for example, in the early weeks?

ASSOC. PROF HAYLEY SMITHERS-SHEEDY: There's no vaccine at the moment, but we're hoping there will be one soon and they've been talking about a vaccine for, I don't know, 50 years before I started research in this area and with no success really. There was a vaccine trialled that was probably 10 or 20 years ago and it had like a 50% impact on transmission - in terms of people becoming infected with the virus, but the new CMVictory and the new nRNA vaccines are hoping to do better, but it's going to be, I think, probably 5 or 10 years before we know about those, yes.

JANE LEE: Thank you. So there's a comment from Stephen Spring here. I'll drop it into the chat. So he's got experience in (inaudible). If there's a PhD who wants to understand more about how genes are provided screening - I'll just move this into the chat, so if there's anybody who would like to reach out to Stephen, please do.

Are there any other questions from people coming through? Otherwise I think some of the - the last question I think to all speakers is what do you think people can do, individual organisations, communities, overall just to advocate and to better preventative health measures for hearing health of children at the local and international levels?

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: I'll go. So I'd like to see - you remember that figure that had the different primary prevention, secondary, tertiary, I'd love to see like an integrated system across all states and territories in Australia and New Zealand and beyond where women are given information that they need to help reduce their risk of CMV infection in pregnancy. Then perhaps women should be screened, I suspect, when they're pregnant and given the opportunity to have antiviral therapies if they need them to reduce the risk of transmission. Then at the foetal level, if we're going to do targeted screening, children who don't pass or are referred after their newborn hearing screening, for them to have the opportunities for treatment, and so on.

So I'd just like to see an integrated process and if anyone wants to join, we're

putting together a disability prevention group for CMV and if anyone would like to join us in advocating for this at government level, please get in touch. Sorry, Duaa, I took too long. Your turn.

DR DUAA GAAFAR: No, all I was going to say among patients and families, it's important to ask the question when you're getting any treatment and ask about possible side-effects and if it happened - if you were to have an adverse drug reaction or a side effect identified early because the early identification helps in further progression of the disease and if there is a chance to do - if you're asked about being involved in research, that is always great opportunity because we all learn from each other.

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: And Pam, did you want to have a last word? Are you right?

PAM ROGERS: I'm okay.

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: You're okay, alright. Thank you so much, Jane.

JANE LEE: Actually, I think - oh, another question has come through. "If states, territories have preschool screening at 3 to 5 years of age, would the screen or hearing test results pick up the cause of hearing loss, such as CMV, ototoxicity, et cetera?"

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: I think we have people on the line like Val, who would know more about screening than I do, but I wouldn't imagine that it would tell you that. I think it would just tell you whether there's a hearing loss or not and then I think there would have to be further investigations.

With CMV, you need to identify it in the neonatal period in the first month of life ideally, three weeks they say, but you can go back and look at newborn screening cards to test for CMV viremia on the newborn blood spot. So if you have a later onset hearing from a progressive sensorineural hearing loss perspective, it's good to keep it in mind that you can go back and test the newborn screening card. There are some issues with that test, but it's something you can do because you can't go back in time to the neonatal period in any other way.

JANE LEE: And another question. "If I heard correctly, it was mentioned earlier that government newborn hearing programs do not follow up CMV

under the targeted surveillance program, but in Queensland if a child is found to have congenital CMV, they're referred for follow-up."

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: That's great. That's fantastic because all children who are identified with congenital CMV should be followed up. I think up until 5 years of age they should be seen regularly to check for hearing, particularly if they have symptoms in the neonatal period, obviously, but even still, good to follow up children born with CMV because they can have that progressive hearing loss. Also, Queensland is particularly lucky because they've got the wonderful Julia Clark, who's been doing some amazing work up there as well, so a shoutout to Julia.

JANE LEE: Alright. I think maybe there - I'm just checking to see if any other questions are coming through. I think that's all. I want to thank our speakers, such great insights today, just some of the things about, you know, how 50% can have CMV in childhood, one baby born every day has disabilities, hearing loss can impact 34 million people - some great insights there. Please feel free to share your insights.

Please help us improve. This is our first time that we're trying to do this. We would like to do a lot more. So I've dropped in the chat a link to our feedback survey. It won't take long to do at all.

Thank you to our speakers. Also, thanks to The Captioning Studio for live captions, Echo Interpreting for Auslan interpreting, accessibility is a big priority for us. And thanks to everyone for taking the time to attend today. We really appreciate it. We know you're busy. We thank you so much for coming today. And again, please take just a moment to complete our survey in the chat. If there's nothing else, thank you all so much for your time today.

ASSOC. PROF. HAYLEY SMITHERS-SHEEDY: Thanks, Jane.

DR DUAA GAAFAR: Thank you very much, Jane.

KATH SWINBURN: Thank you, Jane.

JANE LEE: Alright. Bye, everyone.