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THE TINY PATIENTS

Taking a full-term view

Dr Max Berry is devoted to helping preterm babies enjoy better outcomes. Her legion of tiny patients, and their parents, are right alongside her. If only the grown-ups holding the purse strings would understand...

Words by Lee-Anne Duncan and Images from The Neonatal Trust

In Wellington Hospital's neonatal intensive care unit (NICU), parents wait beside their newborns. They feel helpless, but also helpless to leave. As the nurses move quietly, checking babies, taking notes, reassuring and soothing, the parents look forward to the day they 'graduate' the NICU for home.

And most of the 1000 babies who come into the NICU each year do leave, as the unit has a globally impressive success rate. Due to decades of science and research, with the help of thousands of premature babies, consummate clinical skill and gritted determination, now a 500 gram baby (that's a block of butter) can usually live and grow up. But with what effects?

Dr Max Berry is a Consultant Neonatologist at Wellington Hospital, and a Senior Lecturer for Paediatrics and Child Health at the University of Otago, Wellington. As if two jobs isn't enough, she also leads two research groups and supervises several of the next generation of scientists and clinicians.

A premature baby's body must suddenly adjust to tasks it's not ready for; their lungs must breathe, their tiny, immature gut must process milk. All of these challenges – and so many more – could have far-reaching implications.

Traditionally, if NICU-graduates appeared healthy as children, it was anticipated they'd be healthy as adults. Research now shows that adults born early can be predisposed to major conditions, such as diabetes, hypertension and even issues with their own pregnancies. That's known as the DOHaD (Developmental Origins of Health and Disease) phenomenon.

So, while Max and her team are still very much about saving lives, her research is focused on understanding how this difficult start to life influences future health. "If we knew more about how being born preterm affects them when they're older, what mitigations, what changes to clinical practice could we put in place now to improve outcomes?" says Max. >>>

Over the decades, research has driven countless changes to clinical practice. The reason musician Stevie Wonder is blind? He was given too much oxygen when he was born six weeks early, causing retinopathy of prematurity. Research

has shown how to use oxygen therapy safely to maximise benefits without increasing the risk of complications.

All aspects of care for extremely preterm infants must be thought about carefully. “Even things as simple as lifting the legs of a 500 gram baby to change a nappy need to be considered,” says Max. “That means a lot of blood is pushed suddenly from their legs to their main core. An older person’s brain can sense there’s more blood moving and compensates to stop it flooding its brain. A preterm baby can’t. Maybe there are simple things we can do that would stabilise blood flow to the brain? Then we’d do that for all premature babies, wherever in the world they are.”

One of Max’s Phd students, Dr Maria Saito Benz, recently won an award for her work understanding brain blood flow and oxygen levels in preterm babies. Using equipment including a bioamplifier funded by The Neonatal Trust and international financial services company ICAP, she shone infrared light onto a baby to measure oxygen levels in its tissues, rather than just its blood stream, and measured even subtle changes in the baby’s heart rates and blood pressure.

Max says this will help clinicians know the best way to maintain oxygen flow in the tiniest babies. Ultimately we’ll follow those kids up longer term to see how the changes in brain oxygen translate to brain structure and function. Then we can feed back that information, saying, ‘These are the brain oxygen targets we should be aiming for, for these reasons, and this is how to achieve it’.”

While Max and her team are already doing a lot of preclinical and clinical research, there’s so much more she’d like to do. “As well as our local studies, we’re constantly asked to participate in big international studies. Joining forces and having New Zealand babies participate is cruicial to developing evidence-based practice that answers the needs of our children. Frustratingly, our ability to fully participate is limited not by skills or willingness, but by funding.”

Some research is supported through The Neonatal Trust, but for much of it Max relies on the benevolence and understanding of other private and public funding streams. And there’s fierce competition for it (health funding applications currently have a nine per cent success rate) and always a requirement to show a result and a return – the faster the better. This often means Max misses out because children take time to develop.

People’s funding priorities are around adulthood diseases, forgetting that diseases in babies and children have lifelong consequences. If you fund a project looking at strokes and stroke recovery, you’ll know very quickly if it’s effective. But if you’re researching helping preterm babies, you’ll wait years to see a return on investment.

For me as a neonatalist, and as a mum, this funding approach is nuts. We need to get people to understand the value of our work. If you get it right early, you set these kids on a different trajectory to being healthy children and healthy adults, rather than waiting for them to struggle and fail, then putting all the resources in at the end.”

Recently Max had to let go a hugely valued member of her team, a high-skilled neonatal research nurse. They’re “like hen’s teeth”, but Max could no longer afford the nurse’s salary. “Losing her was a huge backwards step. Without her we can’t contribute to many of the studies we’d like to participate in. That’s really challenging because we all must contribute to a greater understanding of what it means to be born preterm, which has huge scope to allow people to manage their health prevent future harm.”

For example, Max has the go-ahead to study glucose regulation in children and adults born full and preterm to see how they process excess frutose, the main sweetner in drinks.

“We know fructose is really bad biochemically and metabolically. If you’re born premature, are you differentially affected by bad environmental factors, such as drinking fructose? We think so, but we don’t know. If we can find out, as an adult they can make informed decisions about their wellbeing. We’re not chasing down ivory tower factoids – this is real world stuff that impacts patient care.”

All this and so much more is why Dr Max Berry’s work, and the babies she saves and who inform her research, are such a vital part of the medical future. And why the funding limitations are so fettering and frustrating.

But Max wouldn’t do any job other than the one her daughter describes as being a “doctor’s doctor”. That’s a doctor who saves lives, and figures out how to do it better.

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