MULTIPLES AOTEAROA Te Takitini o Aotearoa



AUTUMN/WINTER 2022 Our stories, our heroes









Photos contributed by the Multiples whānau around Aotearoa











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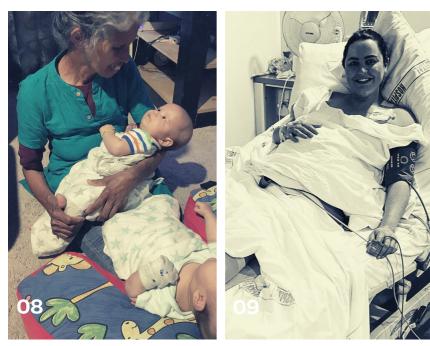
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Multiples NZ Executive

President · Heather Ben 0274841526 president@multiples.org.nz

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Vice President · Desiree Morgan vicepresident@multiples.org.nz

Secretary · Bron Dutton 0274258854 secretary@multiples.org.nz

Treasurer · Sally Coombe treasurer@multiples.org.nz

Marketing and Promotion · Amy Dean marketing@multiples.org.nz

Higher Order Multiples · Sarah Miller tripletsplus@multiples.org.nz

Support Roles

Higher Needs Support · Desiree Morgan specialneeds@multiples.org.nz

Magazine Support Sarah Miller, Claire Nevans & Isabel Plieger

ICOMBO · Carolyn Lister Carolyn@icombo.org

Resources Review & Development · Nadia Fovakis resources@multiples.org.nz

Register, Research Coordinator · Joy Brown register@multiples.org.nz

Magazine Editor · Barnaby Haszard Morris 0273350880 magazine@multiples.org.nz

Resources Distribution resources@multiples.org.nz

Archivist · Refer to Secretary

Grants · Refer to President

Patrons · Mary Lambie and James Mora

Medical Advisor · Dr Emma Parry

Pictured right:

Barnaby, Juney, Tara, Nora Barnaby Haszard Morris Paraparaumu, Kāpiti Coast

EDITORIAL

Ko Maungatautari te maunga e rū nei taku ngākau

Ko Waikato te awa e mahea nei aku māharahara

Nō Tokoroa ahau

E mihi ana ki ngā tohu o nehe, o Kāpiti e noho nei au

Ko Barnaby toku ingoa

Nō reira, tēnā koutou katoa

I'm Barnaby, from Kapi-Mana Multiples, and I'm privileged to have the opportunity to give back to the Multiples NZ whānau as editor of this magazine. A big thank you to the tireless Kirsty for shepherding so many stories into the world as editor. I am excited to continue your invaluable mahi.

I believe we all have heroes in our lives, and stories to tell. It's no surprise that when I asked our community for submissions on this theme, birth stories quickly came to the fore. As Emily Hawker, Simone Szybowski, Marcia Rule, Renee Vaz, and Desiree Morgan share, giving birth to multiples is an intense and extraordinary experience -- and there are heroes along the way, whether it's the little ones themselves or a key support person.

But first, let me tell you about more about how my multiples came into the world. Our story.

In the early days of Tara's pregnancy, I joked that it might be twins. You got pregnant so quickly, I said. She told me to shut up. I didn't really believe it – only one in eighty pregnancies are multiples, or 1000 per year in New Zealand – and we carried on with our lives as best we could.

At the 12-week scan, the sonographer took my joke and made it very real. Two babies were indeed growing in Tara's belly. We laughed, we cried, we freaked out. All of the literature about pregnancy, with its constant references to 'baby', singular, became irrelevant in a heartbeat. Or two heartbeats.

They grew to a combined 5.5 kilograms. It wasn't easy for Tara. The pregnancy stole her keratin, messed with her heart's rhythm, and hard-rewired her brain. She reduced her tea

EDITORIAL (CONTINUED)

consumption to one cup a day to manage incipient atrial fibrillation. She is the hero of this story, like most mothers of multiples.

Our children were born. Two girls. They cried, they ate, they slept (but not always when we wanted them to). We lost our minds in love and exhaustion. People who have struggled with one infant have asked us how we did it. The pat answer is always, we just did it; we didn't know any different. Beneath that, though, is the help Tara and I had along the way – from nearby relatives and friends, from KapiMana Multiples and Multiples NZ, and most of all from each other. We did it together.

The kids are now four years old. They are the most interesting people I have ever met, endlessly fascinating, and a constant enigma. How well do I know them, really? I can identify some of their traits and interests, but as articulate as they are now, there's no language for expressing who exactly they are. Human life defies easy summary.

What I do know is they are different. They were dichorionic-diamniotic in utero – that's two placenta, two sacs – so they are best seen as siblings born at the same time, although with their bright blonde hair and blue eyes, people often struggle to tell them apart. One is more environment focused, the other more people focused. One loves to immerse herself in drawing, the other loves acting out elaborate imagined scenarios. I could go on – but again, these are just my observations from a fixed point in time, likely to be proven wrong at any moment.

As they grow, and we as parents learn how to listen to them, to connect with them, to foster what is unique (and explain why you should at least wear underpants outside the house), they are increasingly full participants in the project of their own raising. We ask them what they think, and they tell us. They're in it together with us, too. And in time, they will be the heroes of their own stories.

The theme for this edition of Multiples Aotearoa is 'Our stories, our heroes'. Just as my children are fundamentally different, every multiples story is unique and fascinating in its own way. My hope is that all parents of multiples are able to tell their own story, at least for themselves, to give shape to the intensity of their experience. And if they are willing to share that story, I hope we can all listen, and learn, together.

Barnaby Haszard Morris Kapi-Mana Multiples



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OUR STORIES, OUR HEROES

Welcome to 2022! Is it me or have the last two years been a combination of slow motion and fast forward all at the same time! For our family we have seen some dramatic changes, and having had COVID go through the house recently, we're now in an amazing space of feeling like we actually are no longer fearful. So now it is time to re-connect with our communities, re-connect with our family and be present (something lockdown has taught or rather reminded me).

For our community we share the same hopes, the hope that we can again get together feeling safe, supporting each other, learning from each other. 2022 will see the first in person National Training Forum in three years! Our last in person forum was Wellington in 2019 where I was elected as President. In November 2022 in Christchurch I will be stepping down after three years as President so let's say it will be three years' worth of celebrating!

I have found many Heroes in our Community over the years, those who quietly, regularly go into our NICUs and give support and guidance in what can be a very scary part of the journey, those who spend hours setting up and packing down playgroup, writing grant applications, juggling children and phone calls or Facebook posts. For me those who have been before, created the path, stood up and been counted, stepped up when everyone was worried they were too busy – they are my heroes. THANK YOU to our amazing volunteer teams who make this organisation tick.

Volunteer Awards

The Multiples NZ Volunteer Awards are now open for nominations. Details and nomination forms can be found on our website and the winners will be announced at the Gala Dinner during National Training Forum.

Volunteer of the month is a wonderful way to show appreciation to a volunteer who has made a difference for you, your family or your club. https://multiples.org.nz/volunteer-of-the-month/

WINZ Home Help Grant – Multiple Birth Criteria

For families who qualify through the Multiple Birth criteria of the WINZ Home Help grant, this benefit is not means tested. You are most likely eligible under this criteria if:

You (or your partner) have given birth to twins or adopted two children from the same pregnancy and have another child in your care under the age of five years old;

OR You (or your partner) have given birth to or have adopted triplets, or higher order multiples (you do not have to have another child in your care to qualify).

You (or your partner) must be a New Zealand citizen or permanent resident, AND you must normally live in New Zealand and intend to stay here.

PRESIDENT'S REPORT (CONTINUED)

Parents who have given birth to, or have adopted, twins can get 240 hours to be used within 12 months. Those who have given birth to, or adopted, triplets or more, are entitled to 1560 hours, to be used within 24 months. Home Help is granted from the date that the babies are born if they are born at home, or from the date that they are discharged from the hospital.

You may use your allotted hours in any way that suits your family needs, i.e. short term full-time help, or longer term part-time help. However, there is no further entitlement once the hours are used up or once the maximum period has ended.

For information on payments and the forms required visit our website - https://multiples.org.nz/government-assistance/

If the home help is provided by an agency that is GST registered, GST will need to be added to the total payment amount. The home helper is responsible for paying his/her own taxes and ACC levies to IRD. In some circumstances, the home helper may also receive financial assistance towards his/her travel costs.

Member Discounts

The Multiples NZ business discount programme continues to be a valuable benefit of membership. We do need to protect these discounters because of their value, which is why we maintain the discount codes within the Members Only section of our website. Access details to the Members Only section are available through our Multiples Clubs.

Heather Ben

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Renee Vaz KapiMana Multiples

My first son was just nine months old when I first found out I was expecting twins, so it was a big shock to the system. We live in Wellington with my family in Taranaki and my husband's family in India.

We made the decision to get my mother-in-law a six-month visa so she could come and live with us when the twins were born to help out. And it was the best decision ever! Not everyone would jump at the idea to have their mother-in-law live with them for six months. Especially in my case where English is her second language and she isn't too confident speaking it. But that would never stop her building a relationship with me and her grandchildren.

So just two short weeks before my twins were born, my mother-in-law arrived in Wellington. She is a lady of service and loves to keep busy and just help with whatever needs to be done. On her first day here, she started mopping floors, doing dishes, folding clothes, and building a relationship with my then 16-monthold son – who she was meeting for the first time.

My twins spontaneously arrived at 33 weeks and my first son spent his first night ever away from mum and dad with his grandma, who he had quickly come to love. She completely took over his routine, taking him on walks to the park, helping feed him, and even took him to Playcentre with other parents (even though she is shy with her English, she did it so my son could go and socialise with his friends).

When the twins came home from NICU, she was quick to help with cooking and cleaning, leaving me to focus completely on my babies and breastfeeding them. She'd help burp them when needed and give cuddles, but never overstepping my role as their mum.

She is the kindest, hardest working woman I know, with a big heart to simply give and help -- all while supporting your boundaries and never getting in the way. She is the superhero who made my transition from one child to three such a smooth ride. I was able to simply be with my babies knowing that there would always be food on the table, the house and cleaning taken care of, and my older son loved and played with.

This photo is my favourite of her and my twins Micah and Ezra. She would hold one while rocking the other between her legs. I am so grateful for the time we got with her. She managed to get home again safely just before COVID first hit in March 2020.



GETTING THROUGH: A BIRTH STORY

Emily Hawker Southland Multiples

"Hi, it's me. You probably need to come home, my contractions have started again."

At 34 weeks and 4 days, I went into what we thought was pre-term labour for the second time in 11 days. When I made that phone call to my husband at 2:30 p.m. on 24 February, my world froze – are the babes developed enough to be born, was this the real thing, am I ready for labour round 3? But the moment we got in the car, I felt a rush of excitement at the thought of bringing the twins earthside soon.

The plan was to head to our midwife, to go on the cardiotocography (CTG) monitor so she could check how the babes were doing. If it looked like labour, then head to our delivery hospital in Invercargill.

After 15 minutes of monitoring, our midwife phoned to let the hospital know we were coming down, unsure if I was heading into active labour or if I was in pre-term labour. Pre-term labour mimics labour but can sometimes prevent your body progressing into active labour. This means no dilation and it can continue for days or even weeks.

We arrived in Invercargill at 4:30pm. I was made comfy in a consult room, hooked up to a CTG, as we waited to be seen. My contractions were there, but mild and not really causing me discomfort. My older girls were happy, they knew mum was back in hospital for checks on the babes and we'd let them know as soon as we knew what was happening.

I was examined by a midwife around 7:45pm and was 2cm dilated, blood pressure was great, babes were coping well, contractions were getting stronger. So before we knew it, we were crossing the hall to our allocated birthing suite, I was changed into a gown, and hooked back up to a CTG. Jase got settled into the room's la-z-boy.

Then our midwife arrived and said to us both, "I think we're having babies tonight..."



I was sitting on the edge of the bed sobbing. My contractions felt like they just rolled into each other. My midwife signalled Jase to come in closer so he can hold my hand. I still remember the pain in my fist from squeezing his so tight. I blocked out what the anaesthetist was saying to the other nurse as she painted my back in some cold liquid.

The epidural needle went in, which meant I was able to get some relief if I chose to, but I was insistent I didn't want one! The team wanted to be sure they could use the line if they needed it for delivery, so they agreed to give me a small dose to make sure my body didn't react. The dose wore off after about two hours so I continued to labour hard into the night with gas and air. I was examined again at 4am to hear the words no woman who has been in labour for 12 hours wants to hear: "NO CHANGE".

After my examination, the tone of the room changed. The team started discussing the fact that maybe my body might be in false/pre-term labour after all. One of the midwifes said the obstetrician was suggesting stopping the contractions again and putting me back on bed rest.

This time I couldn't hold back the tears.

As morning broke, I felt this sense of failure. Why wasn't my body ready? We've been here before, I've laboured easily before, what's different this time?

Somehow, out of the haze of pain relief, I decided to change my mindset. I needed to stay positive, reassure myself that I could do this, and make the best decisions possible for these babes.

A new obstetrician came on shift at 10am. He said he would examine me in three hours, and if I'd dilated to 5cm, he would break my waters and get things going.

No sooner did the door shut behind him that after 18 hours in labour, my contractions all but stopped.

I knew my body was slowing down. I could feel my uterus getting more and more relaxed. I knew that my contractions were getting further and further apart as I was watching them on the CTG. But I also knew that whatever happened today, I need to rest my body and my mind.

For the next three hours, I calmed myself down. I drifted in and out of sleep with every high-pitched beep of the CTG machine and the blood pressure cuff getting tight around my arm every half hour.

I remember saying over and over in my head, "you can't control this. You have to relax."



Jase managed to head out and get a break, grab some lunch – and a quick haircut. All the nurses thought it was hilarious. I said, he is the king of awkwardly timed haircuts – normally on the way to a wedding, though, not when your wife is in labour.

The obstetrician returned to examine me at 1:30pm. We decided not to take the labour-stopping drugs, and if I wasn't dilated to 5cm, I would stay in hospital on bedrest until the babes were ready to come.

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With barely a decent contraction showing on the monitor, I held my breath for what felt like hours as I was examined. I'm a pretty positive person most of the time, but after 21 hours on my back not being able to move, pee, shower, eat, or simply get comfy, I didn't have much positivity left.

But hearing the words "YOU'RE SIX CENTIMETRES" quickly changed that! I looked over at Jase in his la-z-boy with his new haircut. Tears welled up in my eyes as I realised: today is the day we bring the babes into the world and become a family of six.

As my waters were broken, excitement filled my whole body. I was having babies soon and I absolutely couldn't wait.

Almost straight away, my contractions started back up again. Knowing how fierce they were the night before, I was thinking about whether I should get my epidural topped back up.

I had been resisting an epidural during my pregnancy and labour is because it scares me to have the feeling in my body taken away. All I thought was I would be mentally and physically exhausted if I had to do another night with just gas and air.

An hour later I was examined again as my contractions were regular and strong. "NO CHANGE." I'm sorry – what?!

My midwife followed the obstetrician out of my room and when she returned, I knew exactly what they had been talking about. I asked how long I had. She said, he'll give you three hours.

I looked at Jase. He knew how much I wanted to deliver the babes naturally, but we both also knew that if a Csection was the safest option for me and the babes, so be it.

My epidural was topped up enough to take the edge off but not too much that I couldn't feel anything.



My contractions got stronger and stronger. The midwife assured me the epidural was working. After about 15 minutes, she examined me again to see what was happening and said, you won't believe this, you're fully dilated and your babies are coming now...

The room filled up faster than you can imagine. All of a sudden everyone I looked at was wearing scrubs and Jase was standing waiting for instructions.

I froze as I was rolled on my side again and lifted onto the cold surgical bed. All I could do was cry. I was petrified.

Finally Jase was by my side, telling me everything was going to be fine. I was looking up at the big lights that weren't even turned on yet when my midwife said to me, with this funny look on her face, guess what? She lifted up a baby and said, you have a boy! Baby A is placed on my chest. Jase and I are both crying. The room is busy sorting beds for the babes. Nurses start appearing all around us.

Four minutes later, I'm told, "you can push," which is hard with a baby on your chest. One and a half pushes later, another tiny baby is held up in front of us. I don't hear what they say it is as the room is so noisy with monitors and incubators being warmed up. I turn to Jase and ask him. He says it's a girl. More tears.

My heart hurt. I was so relieved they were both here. My hairy little girl was put on my chest next to her brother and all of a sudden, I was a mum of 4 and we were a family of 6.

I look down at our babies. Hemi is still crying but Fiah is yet to make a noise. Both were whipped off my chest and taken to the other side of the room. The nurse to my left keeps telling me, your babies are fine, they just need a little help.

Minutes pass and Jase kisses me goodbye to be with the babies. I'm taken back to the maternity ward to wait to hear from the neonatal unit with an update on how the babies are. An hour has passed and I'm starting to panic again. The door opens just after 7pm and I've never been so happy to see my hubby!

Once the feeling returned to my legs, I was able to walk down and visit the neonatal unit. Hemi was happy snoozing away in his wee bed for the night and Fiah was wide awake in her incubator. I could barely



see her face and beautiful black hair as it was covered in tubes, a cap, and a breathing machine.

I stuck my hand in the little hole so I could stroke her wee arm. I was asked if I'd like to hold her and the tears started again. All I could think was, "this is your fault!" Maybe if I had just listened and stayed on bedrest and not gone into the supermarket that day, none of this would have happened.

I held my sweet girl but I could barely look at her. I kept looking at Jase as I cried, not able to talk. We got back to the room and I broke down. All I kept saying was this is my fault, I should have listened. Why do women blame themselves so much?

Once the weekend was over, I was able to talk to an obstetrician who said my placentas had joined together sometime between my last scan and delivery. My blood pressure shooting up and the fact that I'm 'geriatric' – LOL – all would have contributed to an early delivery. Not a trip to pick up my click & collect!

The reason I wanted to share my birth story is because other women's journeys helped me get through ours. After being born at 34+4 and spending 21 nights in NICU, Hemi and Fiah are now 15 months old and the most amazing gift to our family. I would love some more sleep but being a Mum to multiples is a true blessing.

I hope my story helps one mumma realise that sometimes, we can't control everything this world has to offer.

THEIR BIG BROTHER

Marcia Rule Multiples Canterbury

Lukas, my 13-year-old son, is definitely the apple of my eye! We have always had such a close relationship and it only grew stronger after his father and me separated three and a half years ago.

Without sounding too biased, Lukas is one intelligent cookie. He loves to talk, ask questions and Google everything when he can't find the answer. I remember getting up one morning when he was about seven years old and he was watching a documentary on Nikola Tesla and had so many questions for me. All I could say was, "I have no idea who you are talking about..."



His mind is just so curious. He is also emotionally intelligent. We will often lay in bed together and he will pour his wee heart out to me. He has always wanted a sibling. He even made up a story when he was four and told everyone he had a sister called Ella who lived in Auckland. When we would tell him "that's not true", he would cry and cry.

Now, with Lukas at 13, I am one very lucky mum. He went through a very hard time with some mental health struggles about a year ago and faced some challenges that would see a lot of teenage boys express themselves in negative ways.

However, Lukas just talked about it. He talked to me, his counsellor and sometimes his dad. He would have anxiety attacks in large groups of people and suffered from separation anxiety from me. But as I went through the pregnancy, all this seemed to settle down. Now he dives deep into his love for basketball. He also loves a good game of chess, is very passionate about kapa haka and during his last year at intermediate, he was awarded the Māori leader role! He has an amazing sense of humour and is not afraid to stand up for what he believes in.



"He was involved every step of the way"

When I first found out I was pregnant, Lukas was the first person that came to my mind. He had so much going on already I didn't want even more change for him.

He was going to be starting high school, his dad had started seeing someone new, my parents were living with us because COVID had put a hold on their house build, he was navigating puberty, and his three favourite things in the world had just passed away – his two dogs and his budgie. Now I was about to change his world even more. However, his excitement was like no other. Then to tell him it was twins... it took him a few days to believe me. When we finally found out the genders, and that he was going to get a baby brother, he clenched his fist and did this really subtle "yes". Like he was too cool to get too excited.

I had morning sickness the entire nine months of my pregnancy. Lukas was always very concerned and would often walk or bike down to the shop to get me an ice block or a drink. A few times, I would have to go to after hours for fluids because of dehydration, and Lukas would wait up until I got home just to make sure I was alright.

He was involved every step of the way: pregnancy announcement, gender reveal, baby shower, he never missed a thing. He wasn't allowed at the scans because of COVID, but when he would get home from school, he would always ask me how it went or when my next midwife appointment was so she could check their heartbeats.

Don't get me wrong, he is your typical teenager and is often too cool for mum. But I also get to see a side of him that no one else sees. He is so compassionate, caring, and empathetic. Since our dogs were put to sleep, he really wants to be a vet nurse so he can help animals and their owners.

"Mum, I will be sweet"

The twins' biological dad made the decision not to be involved at just seven weeks into the pregnancy, which was when I found out I was having twins. At first he said he would support me but then after a few weeks of not hearing from him, he messaged and said that it's best if he isn't involved.

Lukas didn't know I'd been seeing someone, so to have to tell him I was pregnant but the dad wasn't around was so hard. I didn't want him to judge me or think less of me. But he didn't. He was just like, "well he is a dick and at least they have a cool brother."

From day one, he wanted to be at the birth. But as COVID got worse in Christchurch and hospital restrictions became tighter, I was told Lukas wouldn't be able to be there because of their no children policy. But Lukas wasn't a small child and I felt the risks of him being there were the same as an adult. In the end, he was allowed there.

I did toss up if it was the right decision because births are so unpredictable. What if something went wrong? I talked to him and he was like, "Mum, I will be sweet, I will just ring Nana and she will come get me."

Because I was induced, I didn't want him at the hospital for hours or days, so the plan was for my mum to drop him off to me closer to the time. I went in Sunday morning. He helped me carry my bags up and get settled and then went home with my mum. He came back the next day and we had some lunch, played some cards, and then he went home with his dad.



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"Can I hold the boy?"

During the birth he was amazing, holding my hand, getting me drinks, and even telling a joke or two. He tried to use a pillow as a shield to block himself from seeing until the midwife said, "your boy has lots of hair." Lukas then dropped the pillow and said, "can you see him?"

At that point the midwife signalled for Lukas to come over and at that exact moment Nīkau Raymond came into the world and was placed on my chest. Lukas shouted, very loudly, "oh my god!" then started dry retching.

For about the next ten minutes, while I was trying to deliver Peyton Grace, Lukas kept saying, "Can I hold the boy?" Both the midwife and I had to remind him that he was still attached to me. 13 minutes later Peyton was born and Lukas stood beside me holding their wee hands and stroking their little fingers.

He then cut the cords, chose their outfits, and got his long awaited hug with Nīkau while my midwife dressed Peyton. He then helped the midwife take all the weights and measurements while on the phone to Nana sharing the news.

"He is my hero"

Lukas really wanted to name Nīkau. It wasn't decided until they were about six weeks old. Some of Lukas' choices were questionable, but eventually, he named Peyton Grace and I named Nīkau Raymond.

Now, Lukas is the most smitten big brother. I had to stay in hospital for a bit due to pre-eclampsia and Lukas just kept asking, "can you come home now? Can I choose their outfits to come home in?"

When we got home, he was a massive help. I tried really hard to not ask too much of him. At the end of the day, he is still a child and I didn't want to take away his childhood because of my own decisions. But to be honest, I don't have to ask much of him because he just naturally does it. He will sit and cuddle the babies all the time and when Nīkau is upset, Lukas will pick him up, lay him on his chest, and Nīkau will just stare at him and watch him talk. Sometimes I catch him lying in my bed cuddling Peyton!

The twins have just started smiling and Lukas gets so excited when he sees it. He reckons they only do it for him. Whenever we go out, Lukas offers to push the buggy and will often tell people how to hold them or what they like. I have just started to notice that whenever Nīkau can hear Lukas' voice his eyes go really wide and he moves his head around until he has found Lukas and then Nīkau eyes stay fixated on Lukas for ages!

I have this amazing relationship with Lukas and I was so worried that having babies would change that. However, it's only made it stronger. I'm so proud to call him my son and to have him as the best male role model for his siblings. In my eyes, he is my hero because at just 13 years of age, he has shown more commitment, compassion, and maturity than the twins' biological dad could even dream of having. He stepped into a role that he never asked for but has never ever once complained about. He just melts my heart.



TWIN HEROES

Simone Szybowski Multiples Otago

I found out at my 12-week scan that I was having twins. I almost fell off the bed when the sonographer said here's the baby, and here's another baby. I was shocked and so thrilled. I'd always thought it would be wonderful to have twins but never imagined that I'd get to.

The journey to their birth had ups and downs, with tests and a lot of scanning needed regarding Twin B's growth. Eventually she was diagnosed with a stable growth restriction.

Finally that all settled down and the specialist was happy everything was stable, but my blood pressure and protein were high. I popped out of work for a quick scan and didn't leave hospital for 108 days.

The girls were fine, and the hospital staff managed to keep me stable for three days. But on the Friday night, it all went pear-shaped and eventually, as the full moon peaked, my girls had to be born via emergency C-section. Born at 5:52 and 5:55 am; Aria-Joy and Imalia-Grace. Weighing 1250 and 810 grams.

It was a relief to hear each of them cry when they were born and a strange experience not to get to see them or hug them. After hours in recovery and then the ward, I was wheeled in my bed to meet them.

The NICU rollercoaster

NICU was a shock to the system the first time. I was very grateful that my girls were alive and cared for but it was also a tough experience to see my babies all tubed and wired up.

It was a rollercoaster in the beginning. We almost lost Imalia-Grace a couple of times in the first week. She was fully reliant on the ventilator and not showing signs of improvement. I couldn't hold her but I would sit with my hand on her back and sing gently to her. She was so sensitive in those early days. Her oxygen levels would drop if a baby cried nearby. She ended up wearing a mask and earmuffs for a while.

The NICU team suggested steroids, which came with the risk of immune suppression. Thank God – they were just what she needed. She had them on a Friday, when they weren't sure if she would live, and by Monday she was extubated, off the ventilator and on a continuous positive airway pressure (CPAP) machine. She improved from there.



Then Aria-Joy had suspected necrotising enterocolitis (NEC), a severe disease of the intestinal tract, and had to get treatment for that. Just as I breathed a sigh of relief for Imalia-Grace, Aria-Joy was now at risk of some very serious problems. Thankfully they got it early enough and she was okay.

Over the weeks, they grew and their CPAP needs reduced. Aria-Joy started breathing on her own, which was so wonderful. She seemed so happy to be free of all the paraphernalia.

SCBU: a smaller, quieter space

We were transported to Nelson SCBU in a private plane after 7.5 weeks in NICU. I was happy to move on, but sad to leave all the superheroes of Middlemore NICU.

SCBU was lovely. A smaller, quieter space. The girls grew and learnt to feed there.

At six weeks in, we were almost ready to leave when Imalia-Grace had an unexpected episode where she stopped breathing. This was really scary and knocked my confidence about going home. It turned out to be a reflux issue.

Eventually, after 7.5 weeks in NICU and 7.5 weeks in SCBU, we went home from Nelson to the West Coast with our precious darlings. Imalia-Grace with her canister of oxygen, still needing the smallest amount. She grew out of needing this after six weeks at home.

Growing and glowing

When I look back now... wow, it was such a full-on time and it seems like a lifetime ago.

It was special to be able to hold them -- Aria-Joy after five days and Imalia-Grace after about a week and a half. Finally holding both of them together the day after that was such a precious moment; a heart explosion. It felt like exactly where they were supposed to be. Next to one another on their Mama Bear.

They are my heroes because of the journey they had to experience in their early days. It's phenomenal how resilient premature babies can be. It's such an unnatural and tough start to life. Miraculously, you wouldn't know they went through any of that if you met the happy, healthy, adventurous, curious, and mischievous wee darlings they are today.

I like to say that they are growing and glowing beautifully. They are running around and exploring everything. They love eating dancing, reading, animals, the outdoors, and playing. I'm so proud of them and blessed to be their Mama.





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TAPS, Identical Twins & Covid – A Story of Surviving

Reprinted from twinstrust.org

It's the start of a new chapter for twin mum Nichola Luther, who has just published her first book, TAPS, Identical Twins & Covid – A Story of Surviving.

The book documents her family's journey through neonatal care and fetal medicine to overcome illness, separation and unimaginable obstacles during the coronavirus pandemic.

Nichola says her book is a story of hope, and she wants to use it raise awareness (and funds) for TAPS – Twin Anaemia Polycythemia Sequence.

At 25 weeks pregnant, in March 2020 and just as the country went into lockdown, Nichola's twin boys were diagnosed with TAPS, a rare complication specific to monochorionic pregnancies, where babies share a placenta.

TAPS happens in only 3-5 percent of monochorionic pregnancies, when small blood vessels form in the placenta between the babies, connecting their blood supplies and allowing a slow passage of blood from one to the other. This can cause the baby donating the blood (donor) to become anaemic (low blood levels), and the baby receiving the blood (recipient) to become polycythaemic (high blood levels), which can lead to overload and strain on the heart.

One of Nichola's boys, Asher, was in cardiac distress in her womb. Nichola, who lives on the Isle of Wight with husband Pete and eldest son, Sebby, said:

"We were under Professor Asma Khalil at St George's Hospital in London. She told us about the laser surgery [to sever the connecting blood vessels] that could be done. She thought that was the best option.

"We had the surgery and that same afternoon, Asma said the vital signs had improved straightaway. The operation went better than expected." At 29 weeks plus five days, Nichola went into labour. Luckily Pete was able to get to her side on 4 April, when they welcomed baby Leo, 1lb 15oz and baby Asher 2lb 10oz.

The twins stayed at Southampton Hospital for four weeks, then transferred to special care on the Isle of Wight before going home the following month.

Nichola's book, launched this year on 3rd March to mark International TAPS Day, which is run by The TAPS Support Foundation, tells readers the family's whole journey. Nichola said: "I thought I would write it down while I remembered it. I just kept writing it. I thought I would see what happens."

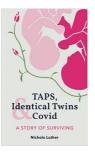
After some positive feedback on early chapters, she kept going, grabbing minutes here and there to write. She added: "It was a story that needed to be told. I needed to get it out. Once my writing got going, it was flowing."

The book became a reality following a phone call with Dr Khalil, who also works at the Twins Trust Centre for Research and Clinical Excellence at St George's Hospital, London. Nichola hoped she could share her story to help others.

"I knew then...it wasn't just something I had written for my family," she said. "Mentally it was challenging. It was very painful to remember parts, as they were horrific. I knew it was very important if I was going to write the book to share everything and not hold back. It also helped me work through a lot of the pain that I'd shut to the back of my mind. Knowing your story could potentially help parents and hopefully save babies. That was so important."

Nichola said that at the time of the twins' diagnosis, she had struggled to find accounts from parents in the same situation.

She added: "There were no stories of hope to grab hold of, only frightening statistics and incomprehensible research. Things have changed since then with the help of Twins Trust and The Taps Support Foundation.



Find out more and order the book at tapstwins.co.uk

"But TAPS is still not routinely checked for. A simple test with MCA Dopplers can change this. Up to 63 percent of cases are being missed before birth."

Nichola wanted her readers to hear the whole story. She added: "I felt like I had to say everything. I didn't want to hide away, it had to be real.

"I really hope that it gives people some hope, that they feel like they are not alone and that they have the power to ask questions.

"I'm still living with TAPS every day with my boys. It's important to highlight and know that there are longterm repercussions, but with the right knowledge and help all children can have the best chance of a wonderful life.

"I still can't quite believe I've written a book. To know that I might be able to help one other parent or save one precious baby, then my job is done and it's all worth it.

"We wanted to be that story of hope. To me, saving babies' lives is what matters and to do this while raising awareness is key."



MULTIPLES WITH HIGHER NEEDS: LITTLE HEROES

Desiree Morgan Multiples Auckland

The theme for this magazine is 'Our stories, our heroes'. So here is our story and why my duo are my heroes. It'll be sentimental, their birthday is tomorrow as I write this and putting it into words is great, but also hard. I should warn you, there will be some descriptions that may be triggering or distressing, so if baby loss, complications, and a baby in life-threatening condition isn't something you are in the frame of mind to read, please stop now.

To get to the hero bit we need to go right back. We had been trying to get pregnant for 18 months, we had looked at fertility treatment and had decided it wasn't for us. I had a beautiful 10-year-old so had already been lucky. So we decided to just be happy with what we had.

Eight weeks later I was at work and felt really dizzy. I thought I needed to eat so took a break and had a snack. Went back to work, still dizzy. Assumed I was coming down with something. As the day wore on I was still dizzy and felt faint and vaguely nauseated. I joked to my workmates that last time I felt like that I was pregnant. As I was laughing I did some quick arithmetic and realised I probably needed to take a test. At afternoon break I got a test and waited.

Surprise, a faint positive. Bloodwork confirmed I was pregnant but my hCG (human chorionic gonadotropin) was low, so I was told to expect another miscarriage. At 5 weeks 4 days, I went to hospital with a bleed, fully expecting to see nothing on the scan, get my anti-D immunoglobin shot and walk out no longer being pregnant.

At a dating scan a few days before, I was told there was one sac, no foetal pole, two blotches that looked like bleeds, and that was it. On this scan, you could clearly see two sacs with foetal poles and little flickers. I joked and said, at least it's not three, as I remembered the two bleeds. The sonographer looked around and found little baby C, also with a little flicker.

Between then and eight weeks I had more bleeds. I was sure I'd lost them every time, but all three were there and had heartbeats. At a specialist appointment at ten weeks, we found out little baby C no longer had a heartbeat, but that the duo looked good. They were hopeful I may get through this without another miscarriage.

The whole pregnancy was eventful. Hyperemesis gravidarum (HG), bleeds, fainting, SPD (symphysis pubis dysfunction), hospital admissions... it was a LONG 37 weeks. The boys' growth had dropped off, and baby B had a couple of weird readings, so when at 37+3 I couldn't feel him move, cardiotocography (CTG) and a quick bedside scan showed his growth had dropped right off and he wasn't moving much. Home to pack, back in the morning, and I'd be induced.

I was SO excited. They had survived and I was going to meet them within the next few days. We went in and waited... and waited... and waited some more. At 2 p.m. they came to put the gel in but I was already 4cm, so we went to the twin delivery room.

There were a few moments where I could have throttled the



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staff because of stupid errors that held up the induction, but finally at 5 p.m. they broke my waters. Nothing really happened so they put me on the Syntocinon drip at 6 p.m. Everyone decided it'd be a good time to go on break as they thought it'd be hours. I reminded them my first birth was only 2.5 hours; still they told me it'd be hours.

I was left with a student doctor, one midwife, my partner and my cousin – they are also my heroes, there are no words to describe how much my cousin being there means to me, and my partner is a legend.

"A born fighter"

Around 6:15 p.m., I tell the student doctor I'll need to push soon. He almost laughs and says it'll be hours. He doesn't check me. I demand the epidural and he calls it in. At 6:25 p.m. I yell at them that I need to push. The midwife checks and half-yells at the student to get everyone back NOW. She holds baby A in while everyone gets in and I get more distressed. Baby A makes his appearance at 6:36 p.m. He's a little stunned after his entrance so I cuddle him, seeing he's breathing and waiting for him to cry.

Something feels wrong. I'm in way too much pain and baby B's monitor starts beeping. Baby A is taken off me and handed to my partner, who is told to get his shirt off and do skin to skin. One doctor is laying on top of me trying to get baby B to turn the right way. After a scan, the doctor jumps off and says we have to go NOW, the red light is hit and we are off.

As I'm wheeled down the hall, they explain I'm bleeding and Baby B barely has a heartbeat so I'm going to be put under for a caesarean section. I tell them they have to save him and they say they will try.

Betadine goes on, then the mask. The last thing I hear is, "we can't find the heartbeat".

I wake up and a doctor explains I lost a lot of blood and both baby and I could have died. I ask if Bub is alive and the doctor says yes, but he's very ill, his chances are slim – around 10 percent – and that if he does survive he will likely never walk or talk.

They wheel me to see him and there's this baby in NICU, huge compared to the other babies in there but still tiny, and he's purple. There are wires in his belly button, he's on a ventilator and he is completely still.

They tell me about his state at birth. His CT scan showing brain damage, and how to give him any chance they need to use hypothermic cooling. Baby A is allowed to have a cuddle while they start cooling in case it is his first and last. And Baby B starts moving and trying to breathe above the vent while his brother is next to him. For three days, I can't touch him for too long or I could warm him up too much. He fights – that boy is a born fighter – and on day five, I'm allowed to actually hold him after they took his umbilical lines out.

"No family is ever alone"

At two weeks old, we finally took him home. He was higher risk for SIDS (sudden infant death syndrome), so we had to be careful, and his immune system was shot from all the drugs he was given to help save him. But he was home.

By 15 months, we knew the boys were different. At age two, Roxas (Baby B) was diagnosed autistic and globally delayed. Dante (Baby A) was diagnosed with ADHD and global delay at four. And they have added new diagnoses since then. Most recently, Roxas has been diagnosed with absence seizures and Dante as autistic and having ARFID (avoidant restrictive food intake disorder).

But these boys live life to the fullest. They know they are different from other kids but they do not let anything stop them. They have this ability to see roadblocks and rather than smash them, they navigate a way around them.



Roxas is doing all the things we were told he would NEVER do. He walks, he talks (oh boy does he talk), he is smart as a whip and can tell you all these amazing facts. He loves to learn.

Dante is my sensitive boy. He protects those that he loves fiercely. He is the first to give you a cuddle in the morning and tells everyone how much he loves them each and every day.

The duo are my heroes because not only have they made it this far through incredible odds, but they have also made me a better person along way. They show me every day what is important and they are the reason I volunteer as higher needs support coordinator and Vice President of Multiples NZ: so that no family is ever alone when things look really dark.

I'm sure we have many more challenges to come, but we also have a whole lot of love, laughter and living to do with my little heroes.





TE AO MÃORI

Te reo Māori pronunciation guide

Learn to pronounce Māori words correctly to become more confident using them. Find out how to pronounce Māori vowels, consonants, and digraphs.

There are 15 distinct sounds within the Māori alphabet. They are:

- five vowels: a, e, i, o, u
- eight consonants: h, k, m, n, p, r, t, w
- two digraphs (two letters that combine to form one sound): wh, ng.

Vowels

While there are only five vowels, combinations of vowels (diphthongs) are common eg. au, ao, ea, oi, ua.

A vowel can also have a long or short sound. A long sound is usually denoted by a macron (a bar appearing over a vowel to indicate it is lengthened during pronunciation eg. ā as in wāhi).

Pronunciation

Vowels are pronounced as follows:

Short

A as in aloud E as in entry I as in eat O as in ordinary U as in to

Long

A as in car E as in led I as in peep O as in pork U as in loot

Consonants

Pronounce consonants as you would in English, with two key exceptions:

T The 't' sound depends on which vowel appears after it. When it is followed by an 'a', 'e' or 'o', pronounce it with as little sibilant sound as possible (almost like a 'd'). When it is followed by an 'i' or 'u', it includes a slight sibilant sound, but not nearly as much as an English 't'.

R Pronounced as a soft 'rolled' r.

Digraphs

The 'ng' digraph is pronounced as it sounds in the English word 'singer'.

The 'wh' digraph originally sounded like the 'wh' in 'whisper', but in most dialects has evolved to be more like the English 'f' sound.

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VOLUNTEER OF THE MONTH

Nominate at multiples.org.nz/volunteer-of-the-month/

Volunteers are the backbone of our Clubs and our community. We would like to acknowledge the hard work of our volunteers through our Volunteer of the Month Award. The Volunteer of the Month award is for volunteers who have provided exceptional service for the betterment of families with multiples within their local area or nationally.

Anyone can nominate someone for a Volunteer of the Month award. Have you received great support from a committee member at your club? Like a much-needed grocery drop in the hazy early days of twin parenting, or a listening ear that really understood when your babies were in NICU? Get their names in so they know how much you appreciate them.

The winners of this monthly award will go into the running for the Multiples NZ Volunteer of the Year Award, which will be announced at the Multiples NZ Volunteer Awards.



Expecting multiples or already have multiples?

Already have a toddler/s or you don't

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Facebook Support Groups

Along with our Multiples NZ Facebook page we also support the following specific needs groups:

- Multiples NZ
- Multiples NZ Neonatal Support
- Triplets Plus NZ
- School Aged Multiples NZ
- Special Needs Multiples NZ
- Multiples NZ Bereaved Whānau Group
- Multiples NZ Public Page
- Multiples NZ National Training Forum Event Page

We support these externally administrated groups:

- Single Parents of Multiples
- Dads of Multiples
- Twins NZ Buy & Sell
- Multiple Birth PND Support NZ
- NZ NICU, SCBU and NNU Parents Support Group

We support our committees through these specific groups:

- Multiples NZ for Committees
- Multiples NZ Presidents Only
- Multiples NZ Newsletter Editors
- Multiples NZ Discount Coordinators
- Multiples NZ Treasurers Only



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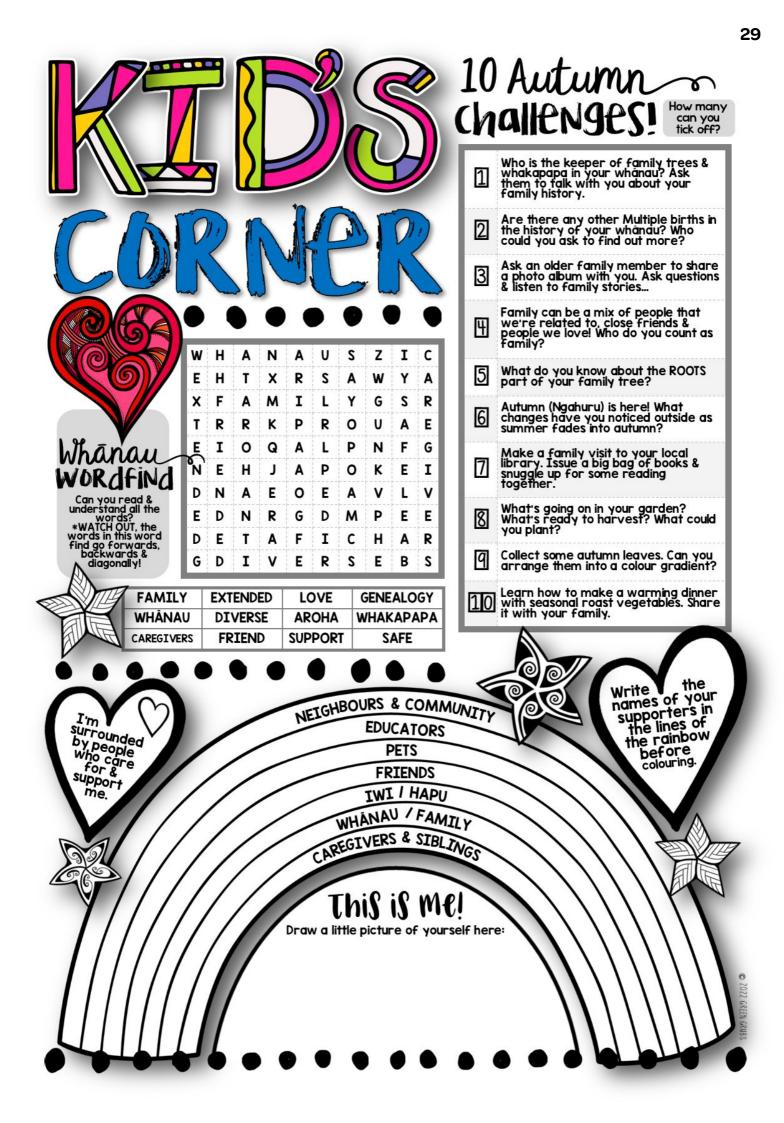
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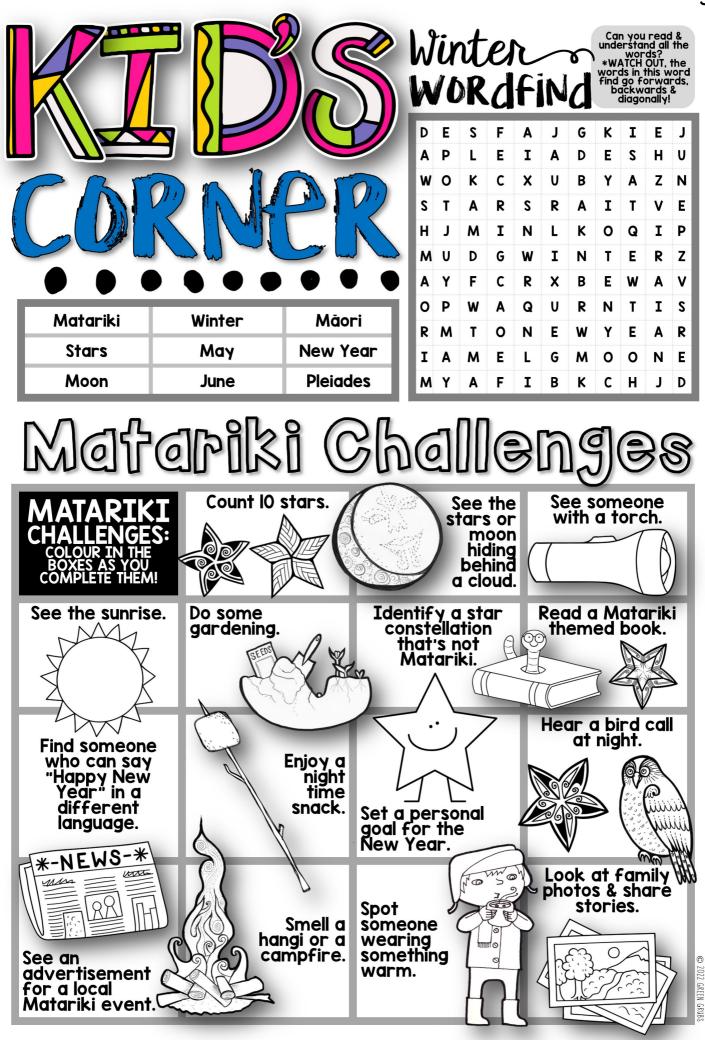


Find your discount code using your club or member login online in the member's area at

www.multiples.org.nz









Local Club Contacts

Northland & Whangarei • Rosie Ponifasio-Hughes • northland@multiplesaucklandnorth.org.nz (Satellite Club) Multiples Auckland North • Thérèse Ellitts • 021 0462398 • president@multiplesaucklandnorth.org.nz • www.multiplesaucklandnorth.org.nz Multiples Auckland Central • Anna Winn • president@multiples-ac.org.nz • www.multiples-ac.org.nz Multiples Counties Manukau • Alison Taylor-Wade • president.multiplescm@gmail.com • www.multiplescm.org Waitakere • please refer to Auckland Central & Auckland North Clubs Hamilton Multiple Birth Club • Michelle Ericksen • 078550373 • michelleericksen@xtra.co.nz • Fiona Stokes-Rouse • 078563330 • hamiltonmultiplebirthclub@gmail.com • www.hamiltonmbc.co.nz Multiples Bay of Plenty • Sarah Mortimer & Becky Klein • president@multiplesbop.org • www.multiplesbop.org.nz Rotorua & Taupo • please refer to Multiples Bay of Plenty Multiples Hawkes Bay • Vicky Bloomer-Chaplin • president@multipleshb.org.nz • www.multipleshb.org.nz Gisborne • please refer to Multiples Hawkes Bay Multiples Taranaki • Sarah Cash • multiplestaranaki@gmail.com Manawatu Multiples • Pamela Perkins • manawatu.mutiples@gmail.com • Manawatutwins.org.nz Whanganui • please refer to Manawatu Multiples Multiples Hutt Valley • Lindsay Hamilton • hvmbcpresident@gmail.com Kapi-Mana Multiples • Ali MacKay • president@kapimanamultiples.org.nz • www.kapimanamultiples.org.nz Wellington Multiples • Amy Elizabeth • president@wellingtonmultiples.org.nz • www.wmbc.org.nz Nelson, Marlborough, Kaikoura, South Canterbury, West Coast • please refer to Multiples Canterbury Multiples Canterbury • Helen Johnson • president@multiplescanterbury.org.nz • www.multiplescanterbury.org.nz Multiples Otago • Elyse Blacow • president.multiplesotago@gmail.com • www.multiplesotago.org.nz North Otago, Central Otago (Wanaka), South Otago (Balclutha) & Oamaru - please refer to Multiples Otago Southland Multiples & Queenstown • Lizzie Stephenson & Sarah Miller • southlandmbc@gmail.com • www.southlandmultiples.org.nz Triplets Plus • Sarah Miller & Tessa Blake • tripletsplus@multiples.org.nz North Island Regional Contact • Ainslee Jacobson South Island Regional Contact • Jacqui Newell

Our free phone number 0800 4 TWINS ETC (0800 489 467) is provided by Multiples NZ to assist people to contact their local multiples club. This number prevents clubs needing to reissue all their flyers when committee members move on. It is your number for your clubs, so please use it as often as you like!

MULTIPLES NZ MISSION STATEMENT

To address the diverse needs of families with multiples through networking, education, support and advocacy. Working in partnership with local Multiple Clubs, community groups, health care providers and educators to ensure our values are upheld.

Te Takitini o Aotearoa 0800 4 TWINS ETC (0800 489 467) www.multiples.org.nz

Nulti



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