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THE Dandelion

THE NEWSLETTER OF FERTILITY NEW ZEALAND, A REGISTERED CHARITY SUPPORTING PEOPLE WITH FERTILITY ISSUES

SPRING 2021



Coming to you 6-12 September!

Did you know that up to one in four New Zealanders will be affected by fertility challenges during their lifetime?

Infertility can affect any of us, regardless of factors including gender, ethnicity, education, religion, urban/rural, and sexual orientation.

Infertility is one of life's toughest challenges, often defined by a sense of loss of control, feelings of isolation and even self-blame, and high stress.

We are proud to bring you **Fertility Week: I am one in four**. It aims to start the conversation and help normalise the experience of infertility and all that it involves. It will give guidance and support for any New Zealander wanting to create whānau or support someone facing infertility.

Join us during Fertility Week, 6-12 September, for:

- a series of virtual information events on a range of topics
- stories as shared by our community
- news
- website resources and guidance
- in-person and virtual support groups

If you, or someone you know, has been affected by infertility, consider fundraising to help enable us to support others walking the difficult road of infertility. Make a quick pledge to our Givealittle page, get sponsors and enter in a local run/walk, or set up a gift registry for birthdays and other occasions through our wonderful partner The Good Registry.

Register as a Member of Fertility NZ (www.fertilitynz.org.nz/register) free of charge to receive our monthly updates via email and get involved during Fertility Week. You can also keep an eye on www.fertilityweek.org.nz and Fertility New Zealand on Facebook. See you there!

www.fertilityweek.org.nz

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For some of us, the fertility journey doesn't go to plan



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How fertility struggles affect wider family





Welcome Notes

Welcome to *The Dandelion* newsletter.

We walk alongside all people facing fertility challenges. This is Fertility NZ's new mission statement which I'm delighted to share with you. Fertility challenges are one of life's toughest journeys and everyone at Fertility NZ is dedicated to making that experience as good as it can be, as well as helping inform people who may be affected in the future. More New Zealanders than ever are turning to us for impartial guidance, support and help on their infertility journeys. It's our privilege to do this every day for people in every corner of Aotearoa New Zealand.

We are looking forward to connecting with many of you during Fertility Week, 6-12 September. This year the theme is 'I am one in four'. A key part of the campaign will be

stories told by many New Zealanders. Our cover story details more about what will be happening and you can visit www.fertilityweek.org.nz to stay up-to-date.

I'm delighted to see some different perspectives on fertility in this issue of *The Dandelion*. On page 4, we hear from a woman whose journey did not end in parenthood. Special thanks for your openness in sharing. In our second story this edition, another woman shares her experience of infertility as a grandparent-in-waiting

Research is key to understanding infertility in Aotearoa New Zealand and driving change to improve experiences and outcomes. Page 7 outlines current research including our own study on Māori and Pasifika

experiences of infertility.

Fertility NZ relies on a network of volunteers around the country who facilitate in-person support and manage closed Facebook groups for their area. The annual training day, facilitated by fertility clinic counsellors, will be held in Auckland during June. This is always a great day to support and connect with these wonderful people.

Wherever you are on your journey, we are here to walk alongside you. Contact your local group (see the back page) or call our Helpline. Connect with us today, and let us know how we can help you.

Warm regards
Juanita Copeland – Chair

About Fertility New Zealand

Fertility New Zealand walks alongside all people facing fertility challenges.

Fertility NZ was founded in 1990 and is a registered charity. It operates on a national level and much of its work is undertaken by dedicated volunteers. Fertility NZ provides assistance for people with fertility issues through the following channels:

- **Support** A network of regular support gatherings, workshops and contact groups throughout the country; an 0800 line and email address for enquiries, and infertility forums on our website where members can provide support to one another.

- **Information** Fertility NZ's website www.fertilitynz.org.nz is the focal point of information; informative fact sheet brochures are available for members and through clinics; regular publication of *The Dandelion* newsletter and email updates to members; conferences and information events. An annual campaign to raise awareness of infertility and fertility issues.

- **Advocacy** Representing the voice of people affected by infertility on medical, ethical and policy issues.

Our vision

Fertility NZ has a vision of a 'fertility friendly' and fertility-aware New Zealand where:

- Infertility is recognised, understood and supported;
- All New Zealanders faced with the medical condition of infertility have access to appropriate, timely and fully-funded medical treatment;
- Men and women have all the information necessary to enable them to make informed decisions regarding their fertility;
- Young New Zealanders learn about fertility preservation;
- Fertility and all alternative forms of whānau-building are respected and valued.

Valuing our egg donors:

The personal and relational nature of donation

While egg donation has become increasingly commonplace, many countries (including New Zealand) report that there are more intended parents than donors. Research into donors' motivations and experiences, including of the process and any longer-term concerns, is limited however, especially in the context of how egg donation occurs in New Zealand, where donors are required to register their information and be identifiable to donor-conceived offspring at the age of 18 (or earlier by application) and where donation is altruistic. Our research team thus interviewed 26 egg donors about their motivations and experiences of donating. Seventeen had donated to those previously unknown to them, six to those known to them, and three to a mix of both known and unknown recipients. Warm thanks to the donors who took part in this study.

In terms of their motivations, we found that donors donating to family or friends were motivated by their close personal relationships, their awareness of the impact of infertility and a desire to help. For those donating to recipients previously unknown to them, donors often mentioned their appreciation of being parents themselves and of feeling moved by the stories of potential recipients, as shared through personal adverts in magazines or online.

Finding out more about the recipients, either through reading clinic profiles, or having some degree of contact online or in person, frequently strengthened their sense of connection with recipients and their motivation to help. Through the donation process, many donors spoke of becoming very invested in the recipients, feeling a sense

of responsibility towards them and interest in hearing about their outcomes. Donation thus became very personal and relational for them, and their sense of connection extended beyond the act of donation itself.

Donors spoke of their donation as a gift, one that potentially made a significant difference in recipients'

Donors spoke of their donation as a gift, one that potentially made a significant difference in recipients' lives.

lives. While most of the donors felt that the donation process itself was a manageable if somewhat difficult process logistically, they downplayed the demands on them, contrasting their experiences with those of the recipients.

On the other hand, many also regarded it as significant act to engage in on behalf of another person/s. Along with this came a degree of expectation that their gift would be acknowledged in some way, not in the form of payment, but through expressions or tokens of appreciation, being informed of outcomes and developments, and keeping to any agreed-upon arrangements with respect to information-exchange and contact.

Donors in our study were very clear that they were not 'mothers/parents' to donor-conceived children, but nonetheless most did speak of feeling connected and responsible in some way for both the children and recipient families. Many donors described



themselves as being 'on standby', always available for information and contact where and when it was needed. At the same time, they were respectful of recipients' position as parents, and careful to maintain an appropriate distance. Some donors were not always confident that recipients would honour prior agreements regarding information-exchange and contact, which created frustration and disappointment.

Donors also appreciated when they had a sense that clinics valued their role in donation through providing them with timely information (both about donation and outcomes), involved them in the process, demonstrated care and respect for their health and wellbeing both during donation and longer term, and provided the option of ongoing support. Unfortunately, many of the donors in our study reported less than optimal experiences and spoke of feeling like they were seen as a means to an end with their needs disregarded.

Most donors were however positive about their experiences overall and had found donation to be a personally rewarding experience. ■

– Dr Sonja Goedeke, Senior Lecturer, Psychology, Auckland University of Technology



Louise's story

Louise* reflects on her journey that ended without a child.

WARNING: this story covers issues around mental health. If it triggers intense emotions, reach out to our support line 0800 333 306 or your GP.

Like many people, my story of infertility is long and complicated. It takes many twists and turns and, unlike those celebrity stories in *Women's Weekly*, it does not end with a 'miracle baby'.

Apart from a patch of intense yearning when I was about 27, I had not really given much thought to having children. In fact, I spent my most fertile years doing everything I could to avoid pregnancy. I was not always successful and I have had more than one abortion. As I write that, I fear your judgement. I can hear a voice saying, "Well, you had your chance." Someone has said that to me, by the

way. And maybe they are right – if you think being a pregnant teenager with substance abuse issues is a chance. Anyway, I don't need your judgement. I have done a pretty good job of beating myself up over all of that.

I didn't get another 'chance' until many years later when I met my Phil. Here was a man that I could see myself having children with. Phil is 12 years older than me and has three adult children from a previous marriage ... and a vasectomy. We knew from the outset that we would not be able to conceive without IVF.

Two years into our relationship, we

had a consultation with a fertility clinic and jumped on the waiting list with confirmation that we would be eligible for two cycles of publicly funded treatment.

I take an antidepressant. I have done for a number of years and I function extremely well doing so. Unfortunately, the antidepressant I am prescribed is associated with congenital heart defects in babies when taken during the first trimester. It can also cause neonatal withdrawal. Determined to give my child the very best start, I consulted with my GP and we decided that I should come off my medication and start on another which was a lot safer.

By the time I got the call from the clinic that Cycle #1 could start, I was well into the process of withdrawal and it was hell. Each day I slipped further and further into a depression of a kind I had never experienced.

This was possibly made worse by the hormone injections I was taking. Long story short, I didn't respond to the treatment and the cycle was cancelled. I was devastated.

I began to think that "someone like me" shouldn't have children. I was clearly unfit. I would pass on my awful genes to an innocent child. I spent weeks Googling "should depressed people have children?". With the help of some good people in my life I eventually decided that my experiences with depression and anxiety could be a strength; something of benefit to raising children. I got back on the horse.

I will not bore you with the ins and outs of treatment, but for those of you who have not had the experience, IVF is a series of injections, blood tests, scans and invasive procedures, followed by a torturous "two-week wait" to find out if the whole thing has been successful.

I must confess that I did the very thing that the nurses at the clinic tell you not to do ... I took a home pregnancy test towards the end of the two-week wait. I was pregnant! The blood test confirmed it and I was over the moon. Phil and I lay in bed at night throwing around ideas for names. We settled on Helena if it was a girl.

Unfortunately we never found out the sex. The first scan revealed what is delightfully termed a "blighted ovum"; there was a sac but it was empty. My body was playing a cruel trick on me. It was still producing pregnancy hormones but I was not actually pregnant. I cannot tell you how much I wanted that sac removed. Stupid, empty, useless sac. It felt like something was holding my body hostage. I eventually had to have a D&C. The anaesthesia was a welcome escape.

I still had one embryo on ice so, as soon as it was possible, we went ahead and had it transferred. Two weeks later I tested and, as they say on the online forums that I had now become waaaayyyy too familiar with, it was a BFN – a big fat negative.

It was about this stage into our attempt to conceive that people started to provide some well-meaning but not very welcome advice. "Why don't you use a surrogate?" it was suggested. If I possessed the energy, I would have explained that there was nothing necessarily wrong with my womb.

"I began to think that 'someone like me' shouldn't have children. I was clearly unfit. I would pass on my awful genes to an innocent child."

We had a bit of a break before starting Cycle #2. We took a holiday and re-set. During that time, friends got pregnant – so easily it seemed, and often in less-than-ideal circumstances. I went to the baby showers and oohed and aahhed at all the appropriate moments, but inwardly I felt jealous and judgemental. It should have been me.

I started my second cycle with renewed hope. I felt positive and more confident knowing what to expect. I managed to produce a handful of good

"I went to friends' baby showers and oohed and aahhed at all the appropriate moments, but inwardly I felt jealous and judgemental. It should have been me."

eggs but only two went on to fertilise and develop as they should.

The first transfer resulted in another BFN. I was down to the last embryo from our funded cycles. I did everything I could to improve my chances of success – eliminated coffee, reduced strenuous exercise, had regular acupuncture, used progesterone pessaries ... and it paid off. I got pregnant!

The joy was relatively short lived. Regular blood tests revealed that my HCG levels were not increasing appropriately. After a few days of this, the nurse told me on the phone, "this doesn't look like a viable pregnancy."

Once again, I felt angry at my body for not cooperating. My acupuncturist posited that my womb was too cold. More reason to hate myself – defective, cold womb! I desperately wanted my period to come so I could move on.

It wasn't until several weeks later that, whilst at work one day, I felt an intense cramp. I went to the bathroom and discovered the "products of conception" which, in a state of weird detachment, I put in a Tupperware container and delivered to Lab Tests. The results showed that the temperature of my chilly uterus was not the problem. The embryo was missing a chromosome; monosomy is the medical term.

It seemed we were at the end of the road. It was a very challenging time and our relationship was sorely tested. At the time, Phil was grieving the passing of his father and his daughter was getting married. I didn't feel supported in the way I needed but I realised that Phil was simply not capable of it.

◀ We met with our doctor at the clinic to talk about our options. The doctor suggested another cycle, this time with some extra protocols, a few tweaks to the process – and \$16,000. I asked what the chances were of this resulting in a live birth. Not quite 50%. We went away to think about it and eventually arrived at a decision ... no more treatment.

I wish I could say from that point on it has been straightforward, but that wouldn't be true. I have had many second thoughts. I seriously contemplated leaving my relationship so I could go and conceive naturally. Family and friends have wanted to find solutions for me. "Why don't you use a donor?" "Have you thought about adopting?" I have felt judged for not pursuing those options; how dare I complain when I haven't tried absolutely everything.

Maybe they are right. I have read the online forums, lurked around the message boards and I realise that many women try a lot, lot, lot more than I did. I occasionally use that to berate myself, but that is happening less now. I have come to realise that this is a deeply personal thing. Where I draw the line is my business. Where you draw the line is yours. No-one could make that decision for me, and I am the one who has to live with it.

Phil's daughter has recently become a mother and that has been very painful at times. In other moments, I cherish spending time with my step-grandson. I may not be a biological mother but that doesn't mean that I am "child-less" and nor do I want to be "child-free", although I am starting to realise some of the silver linings ... the freedom that comes with not having children; the freedom to spend my time exactly as I wish; the financial benefit; the smaller footprint on the planet, and so on.

The biggest challenge for me is finding meaning. Children provide a pretty solid reason for being and in the absence of them, I find myself questioning my purpose, wondering how I can make a contribution to the world.

I am yet to figure that one out. ■



Infertility: A prospective grandmother's perspective

My son and his wife have had issues with conceiving a baby and I have watched as a parent from the sidelines as they have gone through the spectrum of emotions in trying to achieve their goal of having a family.

As a parent I felt absolutely helpless as I could not do anything to assist them or even provide ideas to help them. Despite researching the topic, it was clear that they could only seek guidance from the specialists.

However, what I could do was be a listener especially in the tough times – and there were many. I always felt that was not enough but in fact I discovered that my son and daughter-in-law needed a person they could talk to individually who just listened and understood what they were going through emotionally. They found friends their own age did not fully understand what they were going through and how they felt and therefore they could not confide in their friends. I came to realise that my being their support person was extremely important and critical to them getting through the highs and lows of infertility.

That support helped enormously

by allowing them simply to verbally express their feelings, frustrations, anger and sadness with no sense of judgement from anyone.

For the first time as a parent, I realised that I could not fix the problem – which is what a parent always tries to do. It was well out of my control and all I could do was to be the listener and the support person, remaining strong and positive throughout and not judging their thoughts which were charged with so much emotion.

When my daughter-in-law did fall pregnant I was so happy for them. However, I was still needed as the listener as they were both worried that something would go wrong and that they would lose the baby so the support was required throughout the pregnancy.

I now have a beautiful little granddaughter who has entered this world totally oblivious to the stress and emotional rollercoaster her parents went on in order to have her.

Being a parent /grandparent and watching your children face difficulties such as these can be very hard to cope with. But just being there, listening and understanding, is the best way to help them. ■

FIXX needs more couples

This August the FIIX Study is celebrating its second birthday. Almost 300 couples have joined the study so far. Another 330 couples are needed to reach our goal of 630 couples in the study. If you are currently on the waitlist for IVF, and the cause of your infertility is unexplained, then you may be able to participate.

Around 30 percent of infertile couples in New Zealand have unexplained infertility. The FIIX Study is a clinical trial comparing the two main fertility procedures available through public funding in New Zealand for couples with unexplained infertility. These are intrauterine insemination (IUI) and in vitro fertilisation (IVF).

For more information on these two treatments and how they differ visit our website: www.thefiixstudy.auckland.ac.nz and watch our video.

The FIIX Study is comparing four cycles of IUI with one cycle of IVF. This is because we suspect that these two treatments will result in a similar number of pregnancies and live births.

If you agree to be involved in the study then you are assigned randomly to receiving either IUI or IVF as your first treatment. This means you have an equal chance of being in either treatment group and you will not be able to choose which treatment group to be in. If you are assigned to the IUI group you will receive four cycles of IUI followed by two cycles of IVF until a live birth is achieved or you have completed all treatment. If you are assigned to the



IVF group you will receive two cycles of IVF until a live birth is achieved or you have completed all treatment.

Your participation in the study means your treatment will start earlier than if you remain on the public waitlist, and all your treatment is paid for.

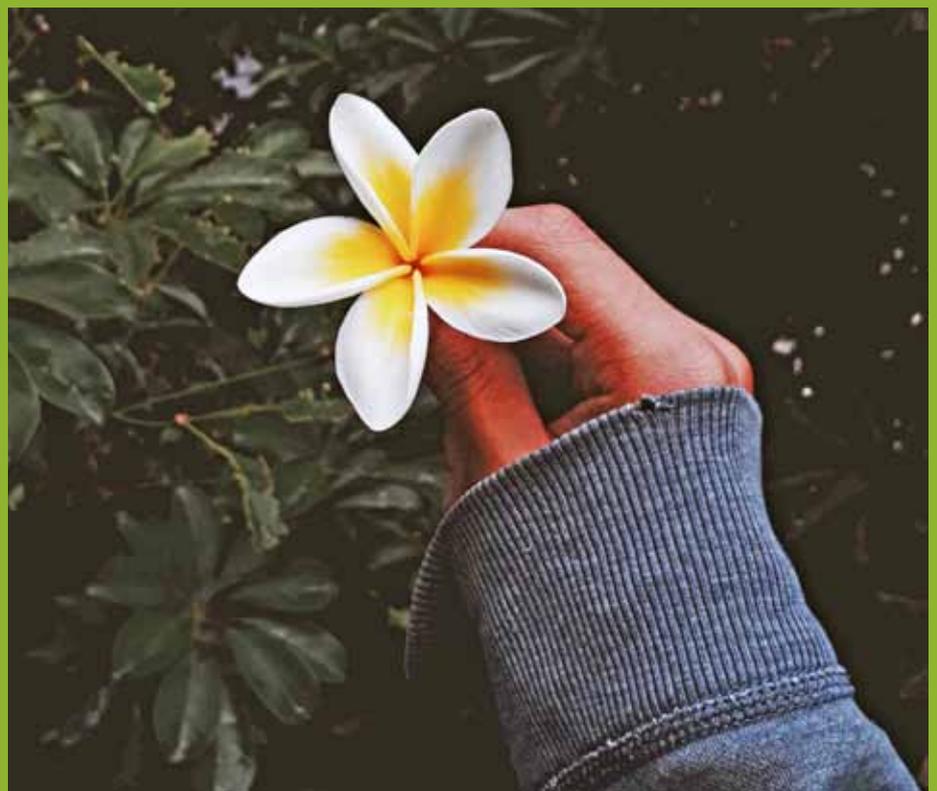
The study is currently available for couples receiving care from Fertility Associates in Auckland, Hamilton, Wellington and Christchurch as well as couples from Repromed in Auckland and Fertility Plus in Auckland. ■

If you would like further information or to enquire about whether you may be eligible please contact: theFIIXstudy@auckland.ac.nz

Māori and Pasifika experiences of infertility

Māori and Pasifika people are no less likely to experience fertility challenges than other ethnic groups in New Zealand, yet are much less likely to seek help. In order to understand the underlying reasons and issues, a research project is underway, largely comprising a series of focus groups. The study, 'Māori and Pasifika experiences of infertility', is a collaboration between the University of Auckland and Fertility NZ. Through listening to and recording the stories of tangata Māori and Pasifika in a series of focus groups held in Auckland, we aim to better understand and drive change through Fertility NZ's support and information offerings, fertility clinics, and other service provision and policy.

Our sincere thanks to the women and men who have so bravely participated and shared their stories in the groups held to date. We look forward to sharing the results in a future edition of *The Dandelion*. ■



noticeboard

Contact your local Support Volunteers for details of group meeting and any questions.

Support information

How can we help you?



Fertility NZ support contacts

Auckland

aucklandsupport@fertilitynz.org.nz
(Casual Coffee, Pregnant After Fertility Treatment)

secondariesupport@fertilitynz.org.nz
(Secondary Infertility)

singlewomensupport@fertilitynz.org.nz

Fertility Support Series

fssauckland@fertilitynz.org.nz

North Auckland
northshoresupport@fertilitynz.org.nz

South Auckland
support@fertilitynz.org.nz

Hamilton
hamiltonsupport@fertilitynz.org.nz

Tauranga
taurangasupport@fertilitynz.org.nz

Hawke's Bay
hawkesbaysupport@fertilitynz.org.nz

Taranaki
taranakisupport@fertilitynz.org.nz

Wellington
wellingtonsupport@fertilitynz.org.nz

West Coast
westcoastsupport@fertilitynz.org.nz

Christchurch
christchurchsupport@fertilitynz.org.nz

Central Otago
centralotagosupport@fertilitynz.org.nz

Dunedin
dunedin-support@fertilitynz.org.nz

Invercargill
invercargillsupport@fertilitynz.org.nz

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AUCKLAND

CASUAL COFFEE GROUP, MT EDEN

Group meets monthly on Wednesdays at 7pm: 21 July, 18 August, 15 September, 20 October, 17 November

CASUAL COFFEE GROUP, NORTH SHORE

Group meets monthly on Tuesdays at 7.30pm: 15 July, 19 August, 9 September, 21 October, 18 November

CASUAL COFFEE GROUP, PUKEKOHE

Group meets monthly on Mondays at 7.30pm: 5 July, 2 August, 6 September, 4 October, 1 November

AUCKLAND FERTILITY SUPPORT SERIES

Semi-structured 3 week course ideal for couples – spaces are limited: 17, 24 & 31 August and 26 October, 2 & 9 November

PREGNANT AFTER FERTILITY TREATMENT

Group meets monthly on Sundays: 11 July, 8 August, 12 September, 3 October, 7 November

SECONDARY INFERTILITY

Please email for details: secondariesupport@fertilitynz.org.nz

SINGLE MOTHERS BY CHOICE - AUCKLAND

Group meets monthly: 25 July, 29 August, 26 September, 31 October, 28 November

HAMILTON

Group meets every third Saturday at 10am: 17 July, 18 September, 16 October, 20 November

TAURANGA

Group meets every two months on a Saturday at 10.30am: 7 August and 11 September

NEW TARANAKI

Group meets monthly on the first Tuesday of every month at 7.00pm: 6 July, 3 August, 7 September, 5 October, 2 November

WELLINGTON

Support and Connect group meets every six weeks on a Wednesday: 4 August, 15 September, 27 October
Virtual Support and Connect meeting held on the first Thursday of each month via Zoom: 1 July, 5 August, 9 September, 7 October, 4 November

CHRISTCHURCH

Group meets on the last Tuesday of every month 6–8pm: 27 July, 31 August, 28 September, 26 October, 30 November

SINGLE MOTHERS BY CHOICE - CHRISTCHURCH

Group meets every 6 weeks on a Sunday: 15 August, 12 September, 3 October

DUNEDIN

Group meets every 6 weeks on a Tuesday 7.30–8.30pm: 3 August, 7 September, 26 October, 30 November

QUEENSTOWN

Group meets monthly on a Tuesday 6.00–7.30pm (winter hours): 13 July, 10 August, 7 September, 12 October, 9 November

INVERCARGILL

Group meets on the fourth Wednesday of every month: 7 September

Fertility Support Series

Our Fertility Support Series is perhaps better described as a 'course' than a 'support group'. Each Series runs on one evening per week over three consecutive weeks. Trained facilitators guide the group through discussions and issues such as communicating your infertility with whānau and friends; and managing the highs and lows of fertility treatment. Participants tell us that the series leaves them feeling empowered, more in control and less isolated. Also, hundreds of great friendships have been formed over the 30+ years these groups have been running, and many of these have endured for decades! We ask for a koha of \$15pp for each participant (for all three sessions). The next Fertility Support Series will be in Auckland from the 17th–31st August 2021, contact fssauckland@fertilitynz.org.nz to confirm your spot on the course.

We are delighted to announce that Fertility Support Series will be coming to Wellington and Christchurch in 2021 – watch this space.

CONTACT US

• phone: 0800 333 306 • email: support@fertilitynz.org.nz • web: www.fertilitynz.org.nz
• post: Fertility New Zealand, PO Box 28262, Remuera, Auckland 1541 • Visit us on Facebook!