



THE Dandelion

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

MARCH 2019

FACT OR FICTION?

Quiz reveals which fertility myths still ring true for many Kiwis

Research tells us that New Zealanders have a relatively low level of fertility awareness. *Fertility Week: Discover your Chances*, held in September 2018, centered around an online quiz which aimed to challenge Kiwis on their fertility knowledge and encourage them to arm themselves with key facts.

As well as highlighting areas for people to grow their fertility awareness, the quiz gave us insight into what Kiwis really know about

their fertility. More than 2,200 people completed the quiz, of which 94% were women. The largest age group was 26–34 (64%) followed by 18–25 and 35–39 (15% each), with 6% of respondents over the age of 40.

A principal objective of Fertility Week is to address – and break down – the myths surrounding infertility. The quiz results painted a fascinating picture of which myths still ring true, and others which may be on their way out!

Myths busted

Smoking doesn't affect your chance of getting pregnant

- It was fantastic that 91% of respondents correctly believed that (women's) smoking halves the chances of pregnancy with both natural conception and IVF. Considering men's fertility health, most respondents understood the importance of avoiding testicular heat and excessive exercise when trying to conceive.

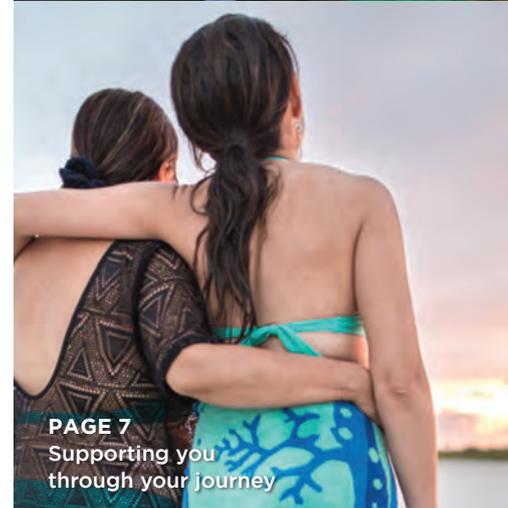
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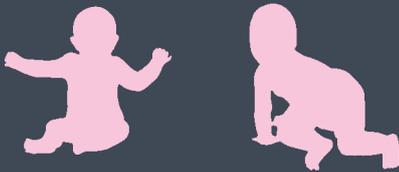
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Supporting you through your journey



IVF HAS UP TO A 50% LIKELIHOOD OF A BABY PER CYCLE





Welcome Notes

Welcome to *The Dandelion* newsletter.

Writing my first column as President has caused me to reflect on the path that led me here. I came to Fertility NZ four years ago to volunteer my time in helping facilitate the support group in Christchurch. My own journey was fraught with isolation and despair – and I wish that I'd known about the support available. I still support the Christchurch group and attend the monthly get-togethers, which centre around positive support, sharing ideas, and hearing guest speakers, with a healthy balance of light-hearted humour! I'm consistently humbled and am so impressed by the support our group members give one another, it really does fuel my passion to support the work Fertility NZ does for our community.

I joined the Executive Committee two years ago to offer my skills and experience in media and public relations. I bring to the President role a passion for supporting and representing all New Zealanders wanting to build whanau. Despite the fact that infertility affects one in four, many people affected (including myself) find the experience incredibly difficult to navigate on a social and emotional level, over and above the more obvious physical and financial stressors. Each person we connect with and support in some way, makes it all worthwhile for us.

At Fertility NZ's AGM in November, we bid farewell to outgoing President Anita Killeen, who served on the Executive Committee for six years. Anita's tenure strengthened Fertility NZ on a financial and governance level, and we are so grateful for

her inclusive, measured approach and the respect she had for the many volunteers that undertake our work. Also at the AGM, we welcomed three new Executive Committee members, who bring with them a diversity of skills and perspectives. Our Committee is now at full capacity, as detailed on page 3.

I was part of the project team for Fertility Week 2018, and part of the campaign was a fertility awareness quiz. I followed the survey results with much interest and was surprised by some of the results as highlighted in this issue.

I'm delighted that Fertility NZ is increasing the breadth of support we offer, including starting dedicated support groups in the areas of donor conception and surrogacy; and living childfree. Both of these groups are beginning on-line, with discussions and webinars, and leading to periodic in-person meet ups, as numbers grow. You can read more about this on page 7.

Fertility NZ exists to support you, and any feedback you have on the information, support and advocacy we provide is always welcome. For those of you who are new readers, *The Dandelion* is the main communication medium we have with our Members and other New Zealanders experiencing infertility issues.

I would like to thank you for taking the time to read *The Dandelion* and look forward to providing support over the coming months.

Warm regards,
Juanita Copeland – President

About Fertility New Zealand

Fertility New Zealand is committed to supporting, advocating for and educating all people who face infertility challenges at all stages of their journey and beyond.

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 men and women 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 whanau-building are respected and valued.

FACT OR FICTION?

◀ From page 1

The best time to have sex during a woman's cycle for conception is during ovulation

- A popular belief was that 'at ovulation' was the best time, however we now know that it's best to have sperm waiting before ovulation, as the egg is at its optimum for only 12-24 hours. 58% of respondents correctly believed the best time for conception to be 2-3 days before ovulation.

IVF is a silver bullet

- Only 8% of respondents believed IVF to have a 70% or 90% chance of success. Most people believe that average success rates are 30% or 50%. Actual IVF success rates in New Zealand are around 50% on average, with the woman's age as the main factor influencing success.

Infertility is a female problem

- (Ugh. We especially hate this one!) 87% believed that male factor infertility is present in either 40%, 50%, or 60% of couples. Only 13% believed that 20% of infertile couples have an issue on the man's side. This was so refreshing to hear – infertility equally affects men and women!

Enduring myths

Celebrities with unlimited access to the best treatments available worldwide are able to conceive their own genetic children, even in their late 40s

- Surprisingly, 53% of respondents believe this to be true. Unfortunately, it's not often published that pregnancies of older celebrity women are virtually always achieved with the help of donated eggs.

The fitter, the better

- The quiz asked whether women who engage in cardiovascular exercise for more than four hours per week have an increased, decreased or the same chance of pregnancy as those who don't. Only 9% of respondents correctly believed that chances are decreased. It's important to exercise – but in moderation. During exercise, be mindful of your internal temperature and heart rate.

Understanding eggs and sperm

Do you know how long it takes for eggs and sperm to mature? Most of our quiz respondents didn't! 66% believed that it takes one menstrual cycle to mature eggs, and most people underestimated the time to mature sperm, either believing it to be 12-24 hours (34%) or 2-3 days (29%).

It takes 90-100 days for eggs and sperm to mature. This is significant as the health of eggs and sperm are influenced by your lifestyle in that period. If, for example, a man is exposed to dangerous chemicals, his sperm may still be affected 2-3 months later. Both parents' lifestyle in the three months pre-conception influences the health of pregnancy, baby, child, adult – and even of future generations (the science is called 'epigenetics').

Thanks to everyone who took the time to undertake our quiz during Fertility Week. We've learnt a lot from your answers. We hope that it empowered Kiwis to build their future whanau!



Fertility NZ's Executive Committee

Fertility NZ is governed by an Executive Committee. Our current Executive Committee was elected at our AGM in November. The Executive Committee is at full capacity, and we are delighted with the range of skills, expertise, perspectives and experiences that our members bring to the table.

Juanita Copeland – *President / Christchurch Regional Representative*
 Brad Edley – *Vice President*
 Lisa Miller – *Treasurer*
 Janet Parker – *Secretary*

Corporate / Medical Members:
 Jo Barnett
 John Peek

General / Consumer Members:
 Jo Catty
 Stewart Dalley – *Rainbow Representative*
 K-J Dillon
 Ali Gale
 Megan Kitchener
 Karina Wong – *Auckland Regional Representative*

Board Advisors:
 Lana Hawkey
 Fiona McDonald
 Antoinette Righarts

Sasha and Rob share the story of their whirlwind romance, which began right in the middle of Sasha's fertility journey...

For better or worse



Sasha's Story, as shared for Fertility Week 2018

In 2016 I was 27 years old, single, had travelled the world, come home and finished studying. I was ready to settle down and start a new life back in New Zealand.

What I had thought was final exam stress taking over my body turned out to be symptoms of premature ovarian failure (POF). This condition, where a woman runs out of eggs prematurely, results in early menopause. As a woman in my late twenties this was devastating news. Finding out about my own infertility before ever having tried for a baby was very difficult to process.

I had no idea POF was even a thing, and up until now I had always been healthy with regular periods. I had always wanted to have children but felt it was important to have lived and experienced the world first, so I had been in no hurry.

Hormone overload

Not only was I faced with infertility, which in itself almost downed me, I was also having to deal with menopause and all that goes with it.

The hormone overload at a time when I was already emotionally weak, along with the hot flushes every 45 minutes lasting 10–15 minutes at a time, 24 hours a day, left me sleep-deprived with little reserve to cope with my situation. All I wanted to do was to crawl inside myself and privately get through this difficult time, but the constant hot flushes made this impossible.

There was no hiding how sick I had

become, and even though I was still getting up and going to work every day there was no hiding from my colleagues or clients what I was going through.

While outwardly they were supportive of my situation (and likely grateful it wasn't them it was happening to) it did take its toll on my career. My constant appointments made me an inconvenience.

A year later I ended up changing jobs to somewhere I didn't feel judged or held back because of something that happened to me, outside of my control. This in part is what has made the decision to go public and share my story even more difficult, but I believe I am now in a place where I am comfortable enough with my situation, that I am able to speak out about it.

"I had no idea POF was even a thing! I had always wanted to have children but felt it was important to have experienced the world first, so I had been in no hurry!"

Now or never

After months of tests and numerous specialist appointments, it came down to if I was ever going to try for my own baby it had to be now. PANIC! In stepped my incredible parents who, without a second thought, offered to support me whatever I decided, even if it meant moving in with them with their potential grandchild.

If it was going to be now or never, I knew I had to try, even if it meant hoping for a miracle. I needed to know that I would be able to look back on that time without regrets, knowing I had done everything I could to make my dream of being a mother a reality.

Again, PANIC! Making the decision was one thing, but where does a student come up with the thousands of dollars it costs for fertility treatment? And where do I get the required sperm when the public system takes several years to be given a donor?

Several awkward weeks followed where I practically begged every male I knew for his sperm. Up until this point I had been pretty quiet about my diagnosis, but desperate times called for desperate measures and a few very uncomfortable conversations. It is amazing how little men know about female fertility.

An unexpected, but very generous, offer from a friend came to my rescue. Not only did he offer to be my donor but he became an incredible support throughout the process. I jumped right in with both feet and was ready to get the process underway. All of my hope was pinned on this one little sperm sample, just to be let down once again when the sample came back as a dud, leaving me with the job of telling my friend – who was so generous with helping me – that he would also be unlikely to have children of his own.

Along comes another friend and another set of tests. Surely this was my chance, but even with a slightly better sample than the first donor, the odds of less than 5% success were hard to swallow.



“Getting pregnant had completely taken over my life for six months and I was turning into a single-minded crazy lady. I decided I needed to accept that it just wasn’t meant to be.”

At this point I had pretty much given up all hope. Getting pregnant had completely taken over my life for six months and I was turning into a single-minded crazy lady. I decided I needed to give myself a break. I had tried everything possible and had to accept the truth that it just wasn’t meant to be.

Along comes Rob. What started as a distraction quickly turned into a whirlwind romance. In no time we became inseparable and I was faced with having to share my diagnosis with him.

After everything I had already been through, this was by far the most

difficult. Where I already knew how I felt about him, the possibility of rejection and losing him was real. I knew him well enough to believe he wouldn’t instantly reject me but I had no idea if he would be able to completely accept me and all my baggage. It shows an incredible strength of character that he allowed himself to love me despite the very real possibility of what may be the ultimate sacrifice.

Support system

From the moment I shared my story with him he has been by my side for every appointment. He has been my main support system through this

journey and has taken it all in his stride.

After letting go of the idea of starting fertility treatment it became a decision of if/when to start hormone replacement therapy, HRT. Weighing up the pros and cons. Hours of research and discussions with my incredible endocrinologist. Eventually the choice was made for me when the symptoms of POF became completely unbearable.

Not long after I met Rob and had told him about my condition, the symptoms increased in severity. I became unable to work, being up literally all night with night sweats and becoming so light headed I would almost pass out every time I was hit with a hot flush.

Rob was incredible during this time, getting up and getting me cold flannels and standing outside with me in the middle of winter as I tried to cool down, then holding me when it finished and I shivered damp in bed.

Months followed of trialling different hormone combinations, trying to minimise side effects, some of which were almost as awful as the POF symptoms themselves. I think 18 months later we have finally found a tolerable balance that I am able to live with long term. I have gained weight during this time (thanks to the hormones) and am having regular bone scans to monitor the decrease in bone density. A woman’s body really wasn’t designed to have a decrease of hormones at such a young age.

I now manage to live a relatively normal, albeit infertile, life. I look back on this time in an almost emotionally detached way. Together we are currently in such a good place where we are so optimistic for the future that it is hard to remember living through such hell.



PUBLIC CEREMONY

Seeds of Hope

Saturday, 4 May 2019,
2.00pm - 3.30pm

Auckland and Wellington

We are holding a Ceremony to acknowledge the losses connected with infertility – childlessness, miscarriage, ectopic pregnancy, acknowledging embryo loss, secondary infertility, and loss of dreams ...

Designed and created by two celebrants who have been on an infertility journey of their own, to assist in the healing process and to provide hope.

- Anglican Church of St Columba & Community Centre, 92 Surrey Crescent, Grey Lynn, Auckland
- Johnsonville Uniting Church, 18 Dr Taylor Terrace, Johnsonville

These events are free of charge. Light refreshments served.

For more information please contact

Keeley Jenkins

Auckland
keeley@kjcelebrant.co.nz

Winnie Duggan

Wellington
winnie@lifeccelebrant.co.nz



Rob's Story, as shared for Fertility Week 2018

◀ I spent my twenties travelling the world and having a good time. I chased winters to New Zealand, Canada and Japan, went on the Mongolia Charity Rally, and backpacked around South East Asia.

While this was all fun, there was something missing from my life. I wanted to find someone special I could spend my life with. Someone to share the adventures with me on a deeper level. On top of this, I always wanted my own kids and think I would make a great Dad.

I met Sasha in early 2017, and we hit it off right away. Early on in the relationship Sasha felt comfortable enough to share with me that she had recently been diagnosed with Premature Ovarian Failure. This was no doubt a very hard thing for her to put forward, not knowing how I would respond. I think it was the right decision to bring this issue to light early in the relationship. It's better to be open and understanding of what each person wants out of a relationship.

Big decisions

I have always wanted to have my own kids, and infertility was never something that crossed my mind. It's rarely spoken about within my circle of friends and society in general. What transpired was a deeper connection and being pushed a little quicker into making some big decisions. I guess they were big decisions, but they didn't seem to be difficult to make. Sasha is super fun to be around, she's smart – cliché I know, but it's true – and we have a blast just hanging out together as well as with our friends. She was someone I could see myself with in the future and starting a family.

Sasha told me the story of when she was diagnosed with POF and how it affected herself and her family. I think she showed an incredible amount of courage asking her friends to donate, and again to move on when it didn't work out. By the time we met, Sasha had somewhat come to terms with the situation – as much as one could.

Since then our relationship has grown from strength to strength. We moved in together, took a long holiday to Canada

where we have both spent our own time chasing the snow, bought a house, and are currently going through the process of finding an egg donor.

Reaching out

We have told a few of our closest friends and our next step is to reach out to a wider circle of friends to inform them of our situation. It's a difficult thing to do. What do you say? Who should you ask? What will they think? As Sasha has come to accept the situation, she is more comfortable and willing to share our story. A decision I wholeheartedly agree with and support.

Where are we at now? Sasha has undergone tests that confirmed there are no eggs left to harvest. There is no reason Sasha couldn't carry a baby to full term, but an egg donor is the only way we would be able to have our own child.

"Sasha told me the story of when she was diagnosed with POF and how it affected herself and her family. I think she has shown an incredible amount of courage."

We have gone to appointments together, had tests done, and applied for government funding. Our funding was allocated to an Auckland clinic earlier this year, and now we are trying to find an egg donor so we can proceed with treatment when the funding is available – hopefully as soon as early 2019.

The key to all this is to openly talk about everything, to support each other, go to appointments together, and share with your family and friends.

If more people talked about infertility, you would be surprised by how common it really is. We hope by sharing our story it will help others on their journey.

• **Update:** *Sasha and Rob's public funding has come through and they are excited about beginning treatment – with a known donor – in the near future. Best of luck, Sasha and Rob!*

SUPPORTING YOU THROUGH YOUR JOURNEY

Facilitators

Our support group facilitators are the backbone of our organisation – a network of amazing volunteers with a simple desire to help others through what they know can be an incredibly challenging time.

A warm welcome to...

- **Laura Bennison** has joined our Dunedin group as a co-facilitator with Jane after recognising how valuable group support is for people going through such a challenging journey. Laura is looking forward to helping others navigate often complex pathways to a child and is willing to help wherever she can through in-person support.
- **Laura Hall** joined our Christchurch group as co-facilitator last December also after finding in-person support invaluable during her journey through treatment. With a background in facilitation, parenting coaching and supporting foster parents, she is looking forward to giving back to others in a meaningful way.
- **Fontaine Maxwell** joined our Gisborne whanau in October of last year after finding the IVF experience challenging, isolating and surreal. Fontaine will be a co-facilitator with Donna, for a newly established group in Gisborne. With knowledge of the Māori world-view and understanding of the additional challenges facing provincial patients, Fontaine is very keen to help others in Gisborne.
- **April Wellington** joins Juanita and Laura in co-facilitating the Christchurch group. A former group member, April knows the value of peer support.

Highlights and motivations Pregnant after Fertility Treatment (PAFT)

“This group ebbs and flows as women become pregnant and join, then proceed to have their baby and move on with confidence, strength, and friendships. Members have connected deeper and forged friendships and after having their babies, continue to meet up socially. To me it feels like ‘job done’ to see and



share in their happy ending. And meet their little miracles and see the deep appreciation and delight they have in their child and in becoming parents.” – *Karina, Auckland*

“2018 was the year we established our support group and found our feet as new FNZ facilitators. One of the highlights for us would be seeing the support, love and understanding that members of the group have shown each other. We have watched as relationships have formed outside our monthly catch-ups which means a great deal as knowing these ladies and their partners have people to turn to for support at any time is the whole reason we are doing this. To watch members come out of the darkness of infertility and hold babies in their arms is the main thing that keeps us going.” – *Amy and Aimee, Invercargill*

Single Mothers by Choice

“It’s been a big year. Our Facebook membership has doubled over the past 12 months including single women from all over New Zealand looking to conceive and all at different stages of their journey. Our monthly meetings in Auckland have between four and 12 women at any given time, though averaging seven. Relationships through shared experience is the type of support that has become particularly important for women

with less straightforward journeys to motherhood as they try to navigate a more complicated path and need to seek additional information and sometimes less conventional routes. This has applied particularly to women using donor eggs, donor embryos and/or overseas treatment. It feels like there is a lot of hope, connection and support amongst the members and I hope this will continue through 2019.” – *Rochelle, Auckland*

New Groups

Childless by Circumstance

In late 2018, Fertility NZ started a closed Facebook group for people who are at the end of their fertility journey. This is a safe, non-judgemental space which offers conversation, insight, tips and support. Events and resources will follow. The group is led by two of FNZ’s Executive Committee members, who welcome you into this positive group. Search ‘Childless by Circumstance’ under Groups in Facebook.

Donor Conception and Surrogacy Network

Fertility NZ is pleased to announce that a Network for the donor conception and surrogacy community will be launched during March/April. Designed by counsellors and consumers, our closed Facebook group will be a hub for whanau with children conceived through donor conception and surrogacy; those who are in the process of building whanau; and Kiwis considering donor conception or surrogacy. Donors and surrogates are also welcome to join our network (but please note this is not a forum for donor-matching). Fertility NZ is currently in the process of gathering relevant and current resources for our knowledge bank, finalising mentors who can provide support and lead discussions on particular pathways. If you are interested in joining this network, or providing support as someone who has walked a certain donor conception or surrogacy path, please send an email to support@fertilitynz.org.nz

Turn to the back page for contact details of all our groups.

noticeboard

Support
Group
Dates

AUCKLAND

SINGLE MOTHERS BY CHOICE

Last Sunday of every month
(unless Monday is a public holiday)

24th February, 31st March, 28th April, 26th May, 30th June

CASUAL COFFEE GROUP

Group meets monthly, on Wednesdays

20th March, 17th April, 15th May, 19th June

FERTILITY SUPPORT SERIES

(semi-structured 'course' ideal for couples – spaces are limited)

Tuesdays 5th, 12th, 19th March
Tuesdays 4th, 11th, 18th June

SECONDARY INFERTILITY

(for people who already have one child or more)

Last Sunday of every month
24th February, 31st March, 28th April

HAMILTON

Every third Saturday at 10am
(except for April, June and December)

16th March, 17th April (dinner),
18th May, June (TBC)

ROTORUA (NEW)

Last Wednesday of each month,
6.30pm–8.00pm

27th February, 27th March, 24th April

GISBORNE (NEW)

Thursday 4th April

WELLINGTON

Wednesday 20th February,
Wednesday 3rd April, Wednesday
22nd May, Wednesday 3rd July

WELLINGTON FERTILITY SUPPORT SERIES

(participants attend each week)

Thursday evenings
21st March to 11th April

CHRISTCHURCH

Fourth Tuesday of each month,
6.30pm–8.00pm

26th February, 23rd April

DUNEDIN

Monday night every sixth week,
from 6.30pm–8.00pm

18th March, 29th April

INVERCARGILL

Wednesday 20th February,
Wednesday 27th March, Tuesday
30th April, Wednesday 22nd May,
Wednesday 26th June

Local information

How can we help you
in your area?



Fertility NZ Local Contacts

Whangarei

whangareisupport@fertilitynz.org.nz

Auckland

aucklandsupport@fertilitynz.org.nz

(Fertility Support Series, Casual Coffee, Pregnant After Fertility Treatment)

secondarysupport@fertilitynz.org.nz
(Secondary Infertility)

singlewomensupport@fertilitynz.org.nz

Hamilton

hamiltonsupport@fertilitynz.org.nz

Tauranga

taurangasupport@fertilitynz.org.nz

Rotorua

rotoruasupport@fertilitynz.org.nz

Gisborne

gisbornesupport@fertilitynz.org.nz

Hawke's Bay

hawkesbaysupport@fertilitynz.org.nz

Wellington

wellingtonsupport@fertilitynz.org.nz

Nelson

nelsonsupport@fertilitynz.org.nz

West Coast

westcoastsupport@fertilitynz.org.nz

Christchurch

christchurchsupport@fertilitynz.org.nz

Central Otago

centralotagosupport@fertilitynz.org.nz

Dunedin

dunedinsupport@fertilitynz.org.nz

Invercargill

invercargillsupport@fertilitynz.org.nz

Fertility Support Series

A semi-structured series of group meetings, and our flagship support offering

Our Wellington team are pleased to announce that they will be holding a Fertility Support Series on Thursday evenings from March 21st to April 11th. Especially beneficial for couples, this is an opportunity for people to meet others experiencing infertility, gain support and learn valuable coping strategies. For more information or to register, please contact wellingtonsupport@fertilitynz.org.nz

Our Auckland team are also pleased to announce they will be holding a Fertility Support Series on Tuesday evenings from March 5th to March 19th. For more information or to register, please contact aucklandsupport@fertilitynz.org.nz

This material is supported by way of an educational grant from Bayer New Zealand Limited. The information submitted is intended to assist health care professionals and patients in forming their own conclusions and making decisions, but may not represent a comprehensive listing of all available information on the subject. The views and opinions expressed by the individual presenters do not necessarily represent the opinion of Bayer New Zealand Limited.

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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!