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# THE Dandelion

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

JULY 2019

## FertilityWeek2019 THE missing kiwis

Many of us are **longing for a child**

23-29 SEPTEMBER 2019

Fertility Week is about raising awareness – what infertility is, who is affected by it and options for help in New Zealand. Fertility Week 2019, entitled *the missing kiwis*, addresses the whole-person experience of infertility. Infertility is not just a medical issue – it has significant emotional, social and mental health impacts.

Grief is often experienced, particularly following a diagnosis of infertility and also upon receiving

negative results. People experiencing infertility often feel a deep sense of grief for the children who are ‘missing’ from their lives.

Who are the missing kiwis? Anyone can experience infertility, regardless of their gender, ethnicity, sexual orientation, education, religion and many other factors. *The missing kiwis* represents the diversity of New Zealand society. The longed-for children belong to every community in Aotearoa.

During Fertility Week, 23-29 September, there will be webinars each evening and in-person events around the country. The Fertility Week site – [www.fertilityweek.org.nz](http://www.fertilityweek.org.nz) – will have a host of information and guidance sitting alongside stories shared by people within our communities.

*Fertility Week: the missing kiwis* will provide support and information for Kiwis experiencing infertility to help them navigate through their journey as well as possible. It will explore grief and loss during infertility and include guidance on protecting relationships

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Our beautiful new website is a mine of free information and support

**Infertility doesn't discriminate**





## Welcome Notes

Welcome to *The Dandelion* newsletter.

What is it like to experience infertility? Is it simply a diagnosis which requires a medical intervention in order for it to be cured? A black-and-white situation which just involves the inconvenience of medical appointments? As you are reading this, I'm probably preaching to the converted. But there are still people in our society who do not appreciate the all-consuming nature of a fertility journey; the grief, stress and social impact that often accompanies it. The fact that many people wish to keep their fertility journey private from friends, whanau and colleagues can add to the isolation and feelings of desperation and emptiness.

Hence, we decided that the theme of Fertility Week 2019 should reflect the non-physical side of infertility. The Missing Kiwis, 23-29 September, will explore the emotional impact of infertility. It will also include guidance for friends and family on how to support someone going through infertility. We'd love to connect with you during Fertility Week. Read more about the campaign on page XX

Our team has been working hard to reinvigorate our website, [www.fertilitynz.org.nz](http://www.fertilitynz.org.nz), with the aim of making it more user-friendly. We have restructured the site into journey stages, from 'Planning for a baby' through 'Fertility treatment options' to 'Living childfree'. Each landing page has resources, videos, downloads and stories. We would welcome any feedback you may have.

We are looking forward to our annual training day for support

group facilitators which will be held in Auckland during June. Training is provided by clinic counsellors; and the facilitators enjoy meeting each other and sharing ideas. We are expecting more than 20 support volunteers from all over the country. Our support facilitators are people who have 'been there' and want to help people within their community through their fertility journey. We'd love to hear from you – now or in the future – if you are interested in volunteering some of your time.

If you aren't yet a member of Fertility NZ, join us today (free of charge). You will receive *The Dandelion* via email, plus you can be informed of groups and events near you. Importantly, your membership supports our advocacy work. We are often called upon as a consumer voice in legislative and medical settings. Further, we will shortly be lobbying political parties for increased funding for fertility patients – the larger our membership, the stronger our voice!

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](http://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.

## Many of us are **longing for a child**

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and the importance of prioritising self-care. *The missing kiwis* will feature coping strategies and tips to help people feel more in control of their journey. *Fertility Week: the missing kiwis* will also provide guidance and support for people experiencing secondary infertility (wanting another child) as well as single people and same-sex couples.

Another part of the campaign encompasses Kiwis who know someone experiencing infertility – and especially those who conceived their own children easily and find it difficult to relate to the experience of infertility. Often these people simply



don't know what to say or do. *Fertility Week: the missing kiwis* will provide information on how to support whanau and friends with infertility.

Fertility NZ exists to hold the hand of people on their fertility journey. We look forward to reaching you in September through *Fertility Week: the missing kiwis*. ■

If you are not already a Fertility NZ member, sign up free of charge at [www.fertilitynz.org.nz/register](http://www.fertilitynz.org.nz/register) and you will receive information about Fertility Week (and support all the important work we do!)



## NEED HELP? **ASK CHARLOTTE!**

We welcomed Charlotte Gell into the Support Coordinator role in April this year. Charlotte provides front-line support via the 0800 hotline and support email. If she doesn't know the answer to a question, she engages the Medical Advisors and other experts within our network. Charlotte also coordinates and assists our support groups around the country and is on the Fertility Week team.

Charlotte has been involved with Fertility NZ in a volunteer capacity for the last few years, as our Whangarei support facilitator.

Contact Charlotte on 0800 333 306 or [support@fertilitynz.org.nz](mailto:support@fertilitynz.org.nz). She will be pleased to hear from you!

*FNZ guidance is always impartial – we have nothing to sell, we exist to support your best interests. Contact us (free of charge) for advice or if you need clarification on anything.*

## EGG DONOR STUDY

If you have donated your eggs to another woman (either someone previously known to you such as a family member or friend, or someone not known to you, such as through a clinic), the donation occurred in New Zealand, and you are interested in sharing your views about your motivations for and experiences of donation, then you are invited to participate in this research!

This involves taking part in an interview at a time and place convenient to you. The interview can be either face-to-face (if it's in the Auckland area) or via media or telephone. The interview is expected to take approximately an hour and a half of your time.

The aim is to gain a better understanding of some of the reasons for which women may donate their eggs and to explore their experiences of donation.



The study is conducted by Dr. Sonja Goedeke, Senior Lecturer in Psychology, Auckland University of Technology in conjunction with postgraduate students in Psychology.

If you are interested in participating or have any questions, please contact Dr. Sonja Goedeke.

Email: [sonja.goedeke@aut.ac.nz](mailto:sonja.goedeke@aut.ac.nz)  
Ph: 09 9219999 ext. 7186.



By Sarah Murphy

# My secondary infertility heartache

When Liam and I decided to start a family, we were incredibly lucky to be successful after just one month of trying, straight after our wedding, our lives falling into place perfectly.

I had a rough pregnancy with every symptom under the sun, or so it felt. Morning sickness through the first two trimesters, symphysis pubis dysfunction which made me almost immobile from pain, and gestational hypertension which caused me to be induced, ended in an emergency c-section and a long recovery.

This experience made me nervous to try for a second child after our beautiful daughter Elodie was born in October 2015, even though my husband was keen to try again asap as he had always spoken of wanting at least 4 children.

Once the memories of my painful and uncomfortable pregnancy had faded, we decided it was time to try for a sibling for our little girl. We were blessed a second time and fell pregnant easily again and found it so hard not to share the news with everyone who would listen.

We saw no reason not to tell people early as hadn't had problems before, so let both sides of our family know

and lavished in their excitement for us. Sadly, as happens to one in four pregnancies, it ended in a miscarriage the day of my first scan booking.

## Mixed emotions

I was beyond devastated and couldn't believe it had happened to us. We held onto hope that the bleeding didn't mean what we knew it to mean. We read stories of people who had thought they were losing their baby but turned out to be healthy and now 18 months old and that gave us fleeting hope. But the truth was, our second little miracle had gone and we were left with a mixture of emotions to cope with.

My husband got angry at the universe and, in a typically male response, looked for a cause as he was certain if he could find the reason why it happened, he could shelter me enough to prevent it in the future.

I was just very, very sad and developed some nasty anxiety, but I was endlessly grateful to have told my family as they were the very best support I could have asked for and reminded me every time I faltered that this was never my doing, or my fault.

Once we did begin to try again, we were taking pregnancy tests each



“After the first six months had passed, people starting asking questions about if we would try again. We didn't want to tell them we were starting to worry so just replied with a smile and a simple... 'soon'.”



month expecting to be able to start healing right away with our little rainbow baby. But this didn't happen. Month after month passed and old 'Aunt Flo' came for a visit each and every time, right on cue.

After the first six months had passed, people starting asking questions about if we would try again. We didn't want to tell them we were starting to worry so just replied with a smile and a simple..."soon".

After nearly a year I started to wonder if it was something I was doing wrong. Or was it my husband? The mental toll it started to take was

confusing, panic inducing and frantic. Days ticked by and the gap between Elodie and her would-be sibling grew bigger and bigger.

After almost 18 months of unexplained secondary infertility and after initial appointments with the fertility clinic, I was placed on Letrozole tablets and a monitored cycle to see how I was ovulating. The scans came back good, my husband checked out A-OK, so we just kept trying and we hoped that one day soon we would be successful.

Well-meaning friends or family always said the same thing, "at least

you have your girl, some people can't even have one". This is so true, we were blessed with our daughter – but comparing one person's grief and anguish over infertility, secondary or not, is a very difficult thing to do.

#### **Daily reminder**

Yes, we had our girl to share wonderful moments and milestones with every day, but it was also a daily reminder that I couldn't give her the playmate she was wanting, the sibling to be her best friend through life. It also meant I knew exactly what I was missing and what I had begun to think we would



never get to experience again, so every milestone, no matter how much I willed myself to just enjoy, was tinged with a little sadness.

My body seemed to be telling me I was done having children but my mind and my heart screamed I wasn't finished and that yearning was heart-breaking.

### Anxiety-inducing

I pushed friends away as they had begun popping out their second or third babies and social media was an anxiety-inducing experience for every baby announcement.

I hated it when people would start talking about babies and pregnancy and then hushed themselves because they thought they were being hurtful to me by even discussing it, but the truth is it did hurt!

After four months on Letrozole I had started to lose interest in pregnancy tests as I was so tired of the feeling I would get when the one lonely line appeared, so it was actually my husband who told me to go and take a test one night just days before Christmas. He told me it was just for his sake and since I had one left anyway, might as well do it now.

I tried to explain that it was too early in my cycle, that tests are more accurate in the morning, that it was just another let down in the making,

“Let people you trust know what you are experiencing and how you are coping. You will be amazed how many people have a similar story and can lend a sympathetic ear and a cuddle on a hard day.”

but I did it for him. I remember looking down at the stick, “Is that? I think that's ... no, it's just my eyes. It's so faint, I think my vision is doubling, but... any double line is still A DOUBLE LINE!”

I went out to the lounge and told Liam that I thought we were getting an early Christmas present but he was doubtful too at that faint, teeny tiny little line. I turned my back for two seconds and he had jumped in the car and raced down to the supermarket to buy another, more reliable test.

BAM! Clear as day, two strong lines at just 3 weeks and 4 days pregnant. Yes that long awaited word, PREGNANT!

During the following weeks fear set in – a hangover from the miscarriage. We were constantly reminding each other that IF this one sticks around we will do this and IF this one survives we will do that, but we didn't let ourselves get too excited until the 12 week scan

where our wee babe was alive, kicking and just the most precious sight we could imagine.

My advice if you are reading this, starting your own journey, is to let people you trust know what you are experiencing and how you are coping. You will be amazed how many people have a similar story and can lend a sympathetic ear and a cuddle on a hard day. I was so grateful for how, once people understood what we were going through, they didn't question our diet attempts, the no-alcohol rules, the times we didn't feel up to going to that baby shower or that kid's birthday party. They cared, and they motivated us when we needed it because they understood why we were doing what we were doing.

### Reach out

Reach out to someone if you are struggling mentally to cope with the frantic fears that come with longing for a child. There are resources available and what you are feeling is normal and not to be hidden.

It is hard not to think about what is “wrong” with you when infertility becomes part of your story, to try and find who or what is at fault, but the best thing we did was place our hope in the fertility specialists' hands. Understand you will give yourself and your family the best chance by doing so.

I am now 27 weeks along with Elodie's little sister, who she has affectionately nick-named Rainbow. I have had horrible morning sickness, symphysis pubis dysfunction is killing me all over again and I am feeling every day of this pregnancy – and I couldn't be happier about it! The treatment worked just how it should for us. We got our little miracle and I will cherish every symptom, every nerve pain, every kilogram gained and every time I waddle like a whale because these are the moments we didn't think we would get to experience again, so for that we are endlessly grateful. ■

# VISIT OUR NEW AND IMPROVED WEBSITE!

## www.fertilitynz.org.nz

Did you know that Fertility NZ's website has a vast range of information and resources to help you on your journey?

Information videos, fact-sheet downloads, questions for your doctor, a glossary of terms (all those acronyms!) and more. Subjects range from preconception care through male factor infertility, egg donation and living childfree, to name just a few.

To support you on your journey, our website has information on all our regular groups and events around the country as well as an enquiry form for anything that we can help you with! You'll also find forums where you can connect with others virtually across a range of diagnoses and journeys.

Best of all, everything on our website is New Zealand-centric so you don't need to worry whether the treatments or legal requirements apply!

We have restructured the site to make it easier to find the information that's relevant to you.

Now, you can find resources and support information, together with people's stories, just by selecting one of the six stages that's most suited to where you are on your fertility journey.

We hope it helps – and would love to hear your feedback.

See you there!



The screenshot shows the Fertility NZ website homepage. At the top, there is a navigation bar with icons for Search, Forum, Profile, Logout, and Contact. Below this is a secondary navigation bar with links for Home, Information, FAQ, Support, News & Research, and About. A banner below the navigation states: "Fertility NZ is a registered charity dedicated to providing information, support and advocacy to people experiencing fertility issues."

The main content area features a section titled "Diagnosed infertility" with a green background. It includes text: "Often, coming to terms with the reality that making a baby isn't as easy as you imagined has its own grief attached. We recommend that you take as much control as possible, and have a plan. If you meet the criteria, get on the waitlist for publicly funded treatment as soon as you are able." and "If you already have a child or children and are experiencing difficulty conceiving again, see our page on Secondary Infertility."

Below this is a section titled "Common causes of infertility" with sub-sections for "MEN (approx. 40%)" and "WOMEN (approx. 40%)". The men's section lists causes such as failed vasectomy reversal, retrograde ejaculation, blocked ducts, varicocele, absence of vas deferens, undescended testes in childhood, and autoimmune disorders. The women's section lists tubal problems, endometriosis, disorders of ovulation, and polycystic ovarian disease (PCOS).

On the right side of the homepage, there is a video player titled "Diagnosed infertility" and a video titled "What to Ask Your...". Below the video player is a graphic that says "1 in 4 New Zealanders experience infertility" with four stylized human figures, one of which is highlighted in blue.



# noticeboard

Support  
Group  
Dates

## AUCKLAND

### SINGLE MOTHERS BY CHOICE

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

28th Jul; 25th Aug; 29th Sept;  
27th Oct; 24th Nov

### CASUAL COFFEE GROUP

Group meets monthly, on Wednesdays.

17th Jul; 28th Aug; 25th Sept;  
16th Oct; 13th Nov

### PREGNANT AFTER FERTILITY TREATMENT

Dates coming soon...

### FERTILITY SUPPORT SERIES

Semi-structured 'course' ideal for couples – spaces are limited.

30th July; 6th & 13th Aug;  
8th, 15th & 22nd Oct

### SECONDARY INFERTILITY

For people who already have one child or more.

Last Sunday of every month.  
28th July; 25th Aug; 29th Sept

## HAMILTON

Every 3rd Saturday at 10am except for June and December.

20th Jul; 17th Aug; 21st Sept;  
19th Oct; 16th Nov; 14th Dec

## ROTORUA (NEW)

Last Wednesday of every month,  
6.30pm–8pm. Jul 31st

## GISBORNE (NEW)

gisbornesupport@fertilitynz.org.nz

## WELLINGTON

3rd Jul; 14th Aug; 25th Sept;  
6th Nov

### WELLINGTON FERTILITY SUPPORT SERIES

Semi-structured 'course' ideal for couples – spaces are limited.

17th Jun; 24th Jun; 1st July

## CHRISTCHURCH

Fourth Wednesday of each month,  
6.30pm–8pm.

24th July; 28th Aug; 25th Sept;  
23rd Oct; 27th Nov

## DUNEDIN

Monday night every 6 weeks,  
6.30pm–8pm.

23rd Jul; 20th Aug; 24th Sept;  
29th Oct; 26th Nov

## INVERCARGILL

Fourth Wednesday of every month.

24th Jul; 28th Aug; 25th Sept;  
23rd Oct; 27th Nov

\* Fertility Week events  
– stay tuned for more  
details including guest  
speakers!

## 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)

secondariesupport@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

dunedin-support@fertilitynz.org.nz

### Invercargill

invercargillsupport@fertilitynz.org.nz

## Christchurch Support Group

Our fantastic Christchurch volunteers, Juanita, Laura and April, are pleased to announce a change in time for our support gatherings in Christchurch. The sessions are now held on the 4th Wednesday of every month, and are open to anyone experiencing infertility, new people and partners are welcome. Some sessions will have a guest speaker, last month Jo Barnett a medical herbalist gave a wonderful informative talk. If you are interested in attending an in-person support group in Christchurch please contact Juanita, Laura or April on christchurchsupport@fertilitynz.org.nz and keep an eye out on our website and Facebook page for updates.

**Editor's note:** People consistently tell us that it was initially difficult to front up to an FNZ support group, but they are so glad that they did. The value of shared experience and understanding — people who 'get it' — is immense. If it isn't for you, though, there's absolutely no obligation to come back! Research shows significant physiological and emotional benefits from in-person support; and we are so grateful for the dedicated volunteers who organise and facilitate these groups.

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

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• post: Fertility New Zealand, PO Box 28262, Remuera, Auckland 1541 • Visit us on Facebook!