



THE Dandelion

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

JULY 2020



The year 2020 marks 30 years of dedicated support to people who are endeavouring to become parents.

This year we are reflecting on what Fertility NZ has achieved, and how the landscape has changed, since its inception in 1990.

The driving force behind the establishment of Fertility NZ was a team of volunteers who were dedicated to providing much-needed support and education as well as advocating to achieve the best outcomes for this often invisible part of our society. The inaugural meeting of the NZ Infertility Society (now Fertility NZ) was held in the lecture theatre of Wellington Medical School, and opened by the Governor General, Dame Cath Tizard. At another meeting during Fertility NZ's early days, a workshop of consumers and health

professionals, backed by consumer input and counsellor advice, made the decision to move New Zealand to identifiable sperm donors from that point forward.

The establishment of Fertility NZ was funded by the NZ Police charity 'Operation Wheelbarrow'. The next edition of *The Dandelion* will have the full story. The impact that this fundraiser had was incredible, especially at the time!

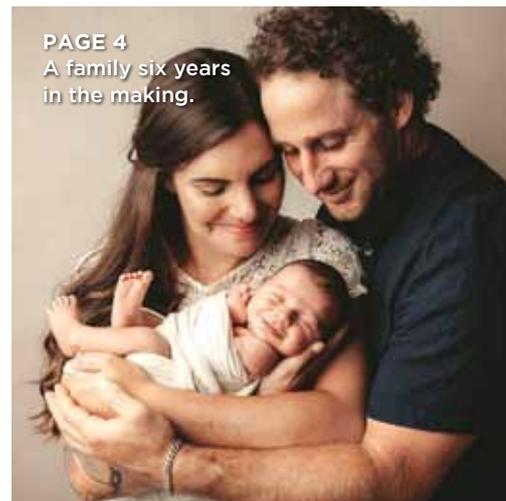
Over the following years, Fertility NZ has supported thousands of people through regional teams of volunteers providing local support, in conjunction with information events and an annual conference. Fertility NZ was largely

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A family six years in the making.



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One man shares his experience of life as donor-conceived.





Welcome Notes

Welcome to *The Dandelion* newsletter.

COVID-19 and the lockdown period has made the last few months extremely difficult for many people in our community. Adapting our services to best support our community was a priority for us, and page 6 summarises the information and support we provided during Alert Levels 3 and 4. I had my own IVF treatment interrupted by the Canterbury Earthquakes in 2010 and 2011. The sense of having all your plans thrown out the window and having no idea when you can resume treatment is upsetting and really scary. I'm so proud that Fertility NZ was able to facilitate the sharing of up-to-date and accurate information to our community and help ease the stress and fear for so many during this time. Our 'Wednesday Webinar' series during Lockdown was particularly popular and I encourage you to set aside the time to watch the

recordings of the information seminars which are relevant to you.

The year 2020 marks a milestone for Fertility NZ. We officially began in 1990, therefore making this year our 30th birthday. Although our team at Fertility NZ is around 50 people strong, only two of these people are paid employees. We could not achieve what we do without a significant army of volunteers and I would like to personally recognise the hundreds of wonderful people who have dedicated their time and expertise over the past three decades. And, of course, all the people that we supported on their journeys over that time. Look out for a campaign commemorating our mahi, on our website and social media in the coming months. If you have used our services in any way at all over the last 30 years, we'd love to hear from you. There are many ways

you can help us grow by sharing what Fertility NZ means to you.

In some respects, Fertility NZ is the club that no one plans to belong to! We exist to help you through the most challenging of times, by helping you navigate through the complexities of your journey, providing advice and supporting you during the highs and lows. If you are new to Fertility NZ, please join as a member (free of charge) at www.fertilitynz.org.nz/register to participate in our Forums, and receive *The Dandelion* via email, as well as information about local groups and events, if you choose.

Fertility NZ is a trusted charity, now with a 30 year history. I'm proud to be part of this organisation, and welcome you to join our community.

Warm regards,
Juanita Copeland – Chair

About Fertility New Zealand

Fertility New Zealand is committed to supporting, advocating for and educating all people who face 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 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 whānau-building are respected and valued.

HAPPY BIRTHDAY TO US!

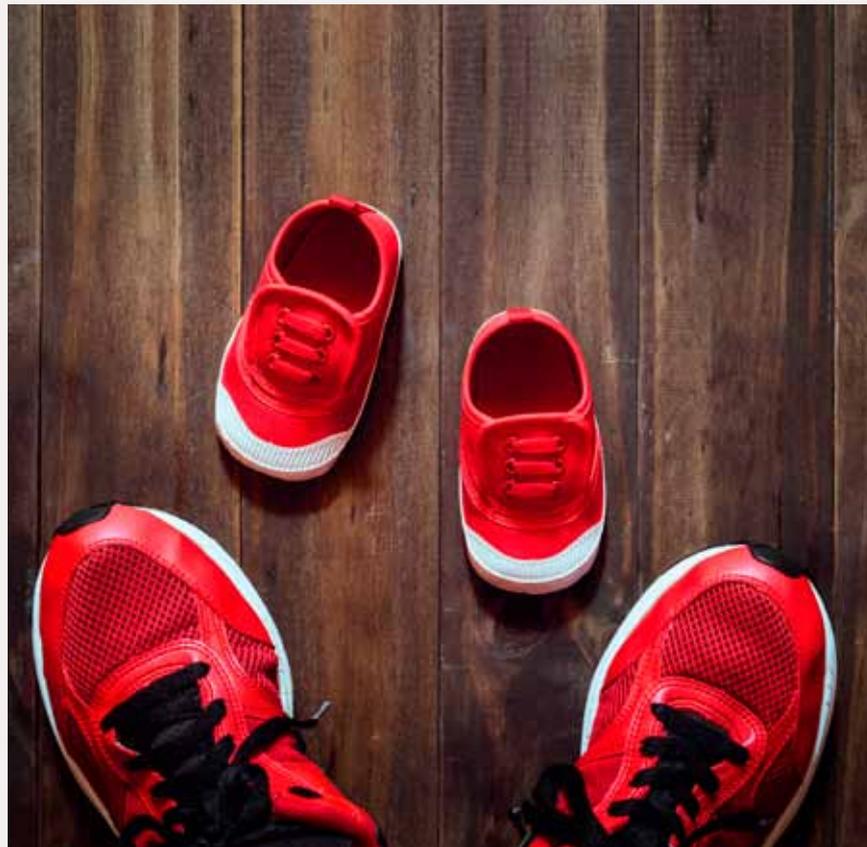
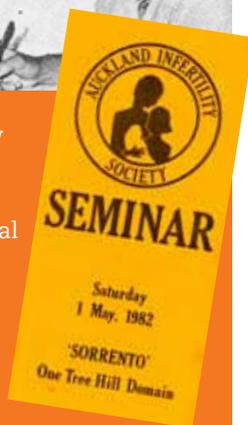
◀ From page 1 responsible for securing a second cycle of publicly funded fertility treatment via Annette King, Minister of Health at the time. Did we support you during your fertility journey? Perhaps your whānau and friends want to do something to help. We are asking our friends and members to pay it forward and help us keep doing our important work by donating \$30 (or any other amount!) via givealittle.co.nz/org/fertilitynz ■



Predecessors to Fertility New Zealand and the New Zealand Infertility Society were the regional infertility societies.

In 1983, news of Dr Freddie Graham's so called 'secret' IVF programme at National Womens Hospital in Auckland was exposed and the programme was temporarily suspended. The recently-formed Auckland Infertility Society campaigned effectively in support of Graham's fledgling programme along with other professionals – speaking openly to the media about their infertility experiences and undertaking fundraising for IVF equipment.

Above: Annette Ellis, Dr Freddie Graham and Joi Ellis discussing arrangements for the seminar in 1982.



Jumpstart your fertility!

Do you want to optimise your fertility by improving your fitness, lifestyle or weight?

Jumpstart is a 10-week programme tailored specifically for people who are wanting to conceive a child It's a positive, goal-focused programme enabling participants to 'jumpstart' their fertility and lifestyle.

Fertility NZ spent a year developing the fertility-specific programme alongside YMCA and Pharmaco Ferring. It is fully customised to each participant and includes guidance for conditions such as Polycystic Ovarian Syndrome

and Male Factor infertility, as well as specialised nutrition advice.

Our initial pilot of Jumpstart during March was interrupted by COVID, so a new pilot programme will start in September, at 12 YMCA centres across Auckland and Hamilton. You can join up alone, or with a friend or partner.

The total cost is \$80 for the full 10 weeks September/ November. Register your interest now to optimise your fertility! ■



www.jumpstartprogramme.co.nz/fertility



The light of our lives

Cassandra Drelizis compares her fertility journey to finding the light at the end of a very dark tunnel.

My entire life I have dreamed of being a mum. I have always been “that friend” that loves and adores everyone’s kids. In 2012 I met the love of my life, Alan, and after two years together we were so ready to start our family.

After six months of trying, we went to the doctors who believed everything was fine and sent us on our way. Six more months passed – and nothing. At this point a referral was made to the hospital for me to see a gynaecologist. There were no obvious signs of anything wrong and we were told, “You’re young and healthy, just keep trying.” After a while and still no luck we did a bunch of tests and a laparoscopy which found endometriosis. I always suspected PCOS but the doctor disagreed.

After the surgery we conceived naturally, but sadly this ended in a miscarriage and D&C. We were

absolutely gutted and could not understand why this was happening to us. We decided we needed to go to a clinic and see the experts which I wish we’d done earlier.

They were amazing. We were finally being taken seriously; I was diagnosed with PCOS as I suspected. Our best option was to try ovulation induction but this didn’t work. Every blood test was bad news. Given this outcome, we now met the criteria for public funding so went on the waiting list. While waiting we decided to try ovulation induction using injections rather than the pills. All the scans and bloods were looking good, however, the day before I was due to have my blood test to see if I was pregnant, I got my period. The absolute high that I was living on was suddenly taken away in one trip to the toilet. Little did I know that this was

going to be my future. Every trip to the toilet, every phone call from a private number, every blood test and every appointment... living in fear, uncertainty, emotional and physical pain.

We couldn’t afford to do any more private treatment so we waited for our funding to come through and in 2017 we started IVF. We had an amazing response and at egg collection we got 21 eggs! Eighteen fertilized and 13 made it to day-5 embryos. We were so lucky and, once again, feeling on top of the world.

Once things were ready, we transferred our first embryo. After a few days I could not help myself and did a home pregnancy test which was positive but again, after getting so excited and planning our future, a trip to the toilet ended everything when I started having a miscarriage. Bloods confirmed what we didn’t want to hear and after another D&C it was over. We were left broken yet again.

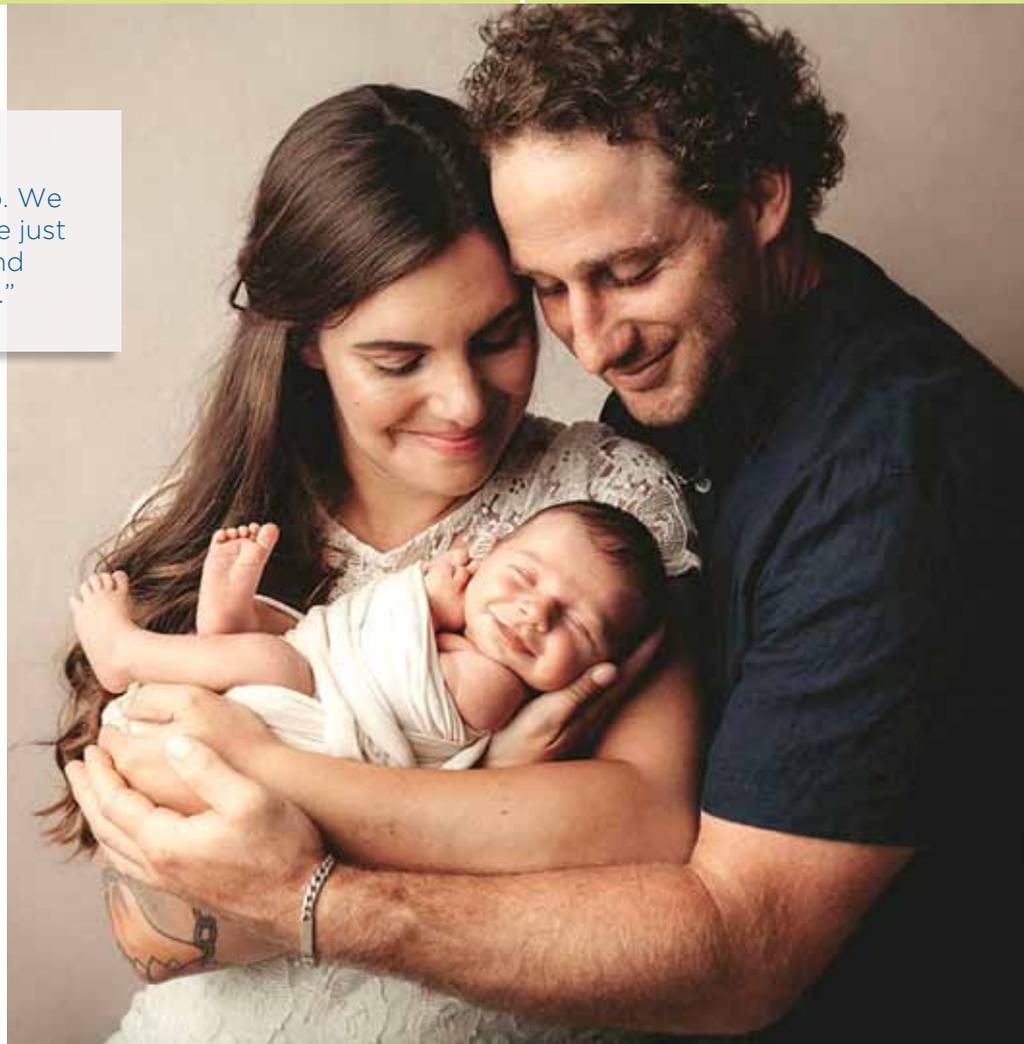
I started to feel like a giant failure, my body was not doing what it was made to do and I could not give the love of my

“We thought long and hard and decided we just couldn’t give up. We wanted a family so badly that we just couldn’t stop. Time helps heal and we just needed some more time.”

life what we dreamed of together. There were times where I tried to convince Alan to leave me as I felt like it was all my fault, but he insisted we were in this together.

At this point we were advised to do recurrent miscarriage screening to rule out anything further and, to our surprise, it revealed that Alan has a genetic condition called Balanced Translocation. We were left pretty shocked and unsure where to go from here, but, very long story short, we were able to carry out PGD testing on our remaining embryos and discovered that seven were OK.

After a little break over Christmas and mentally preparing ourselves again, we transferred our first PGD-tested embryo. This time I waited and didn’t do a home pregnancy test as I just didn’t feel pregnant and I didn’t want to end the small glimmer of hope that I still had... but it did work and I was pregnant! We treaded so carefully in the first few weeks, wondering when this one might end... however it didn’t, well, at least not yet. Everything was going so well until my waters broke at 19 weeks. There really wasn’t much anyone could do other than hope everything would be OK but in reality was nothing was OK and two days later I went into labour and gave birth to our little angel Rose, who was born sleeping.



I was absolutely destroyed. Physically, mentally and emotionally destroyed. I was struggling so bad with everything and with a very unsupportive employer Alan and I decided it was best for me to quit my job and have some much needed time out. The added stress to have another income just wasn’t worth it.

Months later, when we were ready, we tried again – transferred another perfect wee embryo and got a positive pregnancy test. But yet again, another trip to the toilet ended the joy – I was having another miscarriage. My third

D&C later, I was done, I couldn’t do this anymore.

There were so many things in our lives we were missing out on, putting on hold – friendships that I distanced myself from and I could see myself falling into this horrible hole that no one wants to be in. If it wasn’t for the amazing support from a few special people in our lives and the clinic counsellors I don’t think I would have dealt with things as well as I did in the end.

After a review appointment with our specialist, we thought long and hard about where to go from here and decided we just couldn’t give up. We wanted a family so badly that we just couldn’t stop. Time helps heal and we just needed some more time.

When we were ready again, we did a hysteroscopy before doing another embryo transfer and found a lot of scar tissue in my uterus. This was able to be removed and then the following month another embryo was transferred and there I was, pregnant – yet again.



Left: The collection of medications that Cassandra needed to take in order to conceive and carry daughter Maddison to term.

◀ We always suspected the reason Rose was born so early was due to me having an Incompetent Cervix, so I was classed as high-risk and placed under obstetric care. This suspicion proved to be the case, as at 12 weeks my cervix was not looking the greatest so the doctors placed a cervical stitch to prevent us losing this bubba.

I lived the entire pregnancy in fear. We had a few scares along the way and I was so thankful to have fortnightly scans as I was able to have my fears put at ease when everything was actually looking good.

Then our dream for the past six years finally happened, our miracle girl Maddison was born healthy and full term (six days after taking the cervical stitch out).

Our hearts are so full and as much as everything we have been through has been absolute hell on earth, Maddie makes it all worth it now. To think that we were so close to giving up, Maddie wouldn't be here today if we did. She honestly is the light at the end of the very dark tunnel we were once in. She is now 4 months old and is the centre of our world.

During our journey we have met some amazing people and made life-time friendships. I also had the honour of joining the Fertility NZ Wellington Committee. The support they gave to me over the years I want to return and do the same for others.

With four embryos left we can now look forward to the future and stop living in this constant fear, uncertainty and pain. ■

Our support volunteers know the heartache of infertility first-hand and dedicate their time and energy to supporting others in their community through their journey. Cassandra is part of our wonderful Wellington team which meets regularly for 'Coffee and Chat' – a no obligation chance to connect with others in the same boat who 'get it'. See the back page for details or email wellingtonsupport@fertilitynz.org.nz

How has the Covid crisis affected you?

How are you doing? It's true that the word 'unprecedented' has been overused this year, but it truly has been a crazy time.

A sense of loss of control is very common to people experiencing fertility challenges. The arrival of COVID-19 in New Zealand and the subsequent lockdown really exacerbated this for many of us. Treatment cycles were cancelled part way through, and much awaited treatments were postponed (at the time, we didn't know how long for). Fertility is time-critical and for many, the sense of further precious time passing along their journey was highly stressful.

At Fertility NZ, we adapted our programmes and our entire team dedicated themselves to doing what we could to help people. During March and April, our Helpline received 80% more enquiries than it did during March-April last year. We hosted information webinars every

Wednesday during Alert Levels 3 and 4 which were really well attended. Our wonderful Support Volunteers around the country held group meetings virtually and/or kept in touch with people via phone.

Now, fertility clinics and other service providers are working hard to catch up on the back log and meet everyone's needs. As always, we are here for you and ready to hear what support or guidance would be useful to you. Perhaps your situation or options have changed post COVID and you need some advice from an impartial source? Our help is free and supported by a panel of experts.

We always feel privileged to support and guide people through the challenges of a fertility journey and we understand the significant need over the last few months.

Our best wishes and thoughts are with everyone in our community as we return to a sense of normality. ■

Webinar recordings from COVID-19 Alert Levels 3 and 4 are available on the News section of www.fertilitynz.org.nz. Check out:

- *Endometriosis & Fertility* – with Prof Neil Johnson and Deborah Bush MNZM
- *What happens in the lab?* – with Jeanette MacKenzie
- *The top 6 things you can do when trying-to-conceive* – with Jo Barnett
- *What happens in a typical IVF cycle? Why IVF might be right for you* – with Dr Andrew Murray and Dr Mary Birdsall
- *Recurrent Miscarriage* – with Dr Pete Benny
- *How to find an egg/sperm donor or surrogate* – consumer panel
- *Timing of Sex* – with Dr Karen Buckingham
- *Fertility and Nutrition* – with Alice Gormack



Are you a parent via donor conception or surrogacy, or thinking about becoming one? Kevin* shares his insights on growing up, learning his origins and how it changed his perspective on his whānau.

Reflections of a donor-conceived adult



Life presents scenarios through which we grow, right? For the most part, I choose to look at things this way – to be positive and face challenges head-on. But there's one thing in my life that gets me, one thing that attitude alone doesn't seem to solve.

And it is this: things that I held dear, things that I found comfort in, my view of family, are not as I was led to believe. And it was only 'untrue' because I was presented with an alternative by those I love – a story with a secret.

I'm 50 now and this still gets me.

Please don't get me wrong, I love my family and appreciate everything they have done for me. I am very grateful for decisions made. How could I not be?

I also get that the time and period of my conception wasn't conducive to openness. And the clinicians involved need to hear this. 'Go home, make love and forget about it' was the mantra of the day – and the start of the problem. So I get the predicament too.

A secret revealed

But there's a point where this gets personal, it has to for me at least, because one day things changed. And the secret that was revealed to me then, at 16, was then mine to keep.

At 16, I needed to reconcile the shift in my family story – that my father was infertile and I was donor-conceived. My deep love for my parents remained unquestioned – if anything, it became stronger as I considered the hardship and sacrifices they had made.

What do I do, now that so much

has happened, now that so many relationships have formed, knowing what I know now? At 16, I chose to rebuild in private. At 50, I still have to, to honour the legacy of my father.

But it didn't have to be this way.

Clear answers

Yes, being 'surprised' that day did hurt. I remember it like it was yesterday. We understand 'telling early' is a better way to go today. But even so, that didn't change who 'DAD' was and who 'MUM' was.

Any efforts in my 30s to find my donor were with mindful regard to this. What was pushing me to explore this further? What was I hoping to achieve? My answers were clear – to better understand myself. Not to find long, lost relatives from the past, or review the special relationships I held so dear.

What incredible choices my parents made, through a journey that was no

doubt very tough for them. Regardless of the challenges, they made a shared choice to be in this together and to create their family in the best way they believed possible.

They needed to travel to Australia (there was no such procedure in the late 60s in New Zealand) which cost them, both emotionally and financially, with no guarantees of a result. What an act of love and commitment to their future family. And mine.

The mere consideration of this made me feel more loved, more wanted, and just a little bit special. These days donor-conceived people also have better access to information due to a more open society. But even back then, and after my searching some 16 years later, I felt loved and lucky my parents made the choices they did.

Thank you to MUM and DAD. And to one amazing donor out there. ■

Join our Donor Conception & Surrogacy Network

The Donor Conception & Surrogacy Network exists to support people considering creating whānau with the help of donors or surrogates, people currently on a journey, and parents through these means. It's a space for support, community and sharing of ideas and tips. It's not a space for finding a donor/surrogate (although you can ask others for advice), or any judgement. Our Network has so far hosted three information webinars: *Legal Aspects of Donation and Surrogacy*; *Telling my child's donation/surrogacy story with confidence*; and *How to find an egg donor, sperm donor or surrogate*. The recordings are available for you to watch at your leisure. Once viable, the Network will hold in-person information/support meetings in the main centres around New Zealand once or twice per year. We welcome you to join – search Donor Conception Surrogacy NZ in Facebook Groups (your identity is only visible to others within the group. Screening questions apply).

*Not his real name. Many thanks for your generosity of spirit and for your insights.

noticeboard

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

AUCKLAND

CASUAL COFFEE GROUP, MT EDEN

Group meets monthly on Wednesdays at 7pm: 15 July, 19 August, 23 September, 21 October.

NEW CASUAL COFFEE GROUP, NORTH SHORE

Group meets monthly on Tuesdays at 7.30pm: 8 August, 15 September, 20 October.

NEW CASUAL COFFEE GROUP, PUKEKOHE

Group meets monthly on Mondays at 7.30pm: 3 August, 7 September, 5 October.

FERTILITY SUPPORT SERIES

Semi-structured course ideal for couples – spaces are limited: 28 July, 4, 11 August; 6, 13, 20 October.

PREGNANT AFTER FERTILITY TREATMENT

Group meets monthly on Sundays: 5 July, 2 August, 6 September, 4 October.

SECONDARY INFERTILITY

Monthly meetings, please email for details: secondarysupport@fertilitynz.org.nz

SINGLE MOTHERS BY CHOICE

Last Sunday of every month at 10.30am: 26 July, 30 August, 27 September.

HAMILTON

Group meets every 3rd Saturday at 10am: 18 July, 15 August, 19 September, 17 October.

TAURANGA

Group meets every two months on a Saturday at 10.30am: 25 July, 26 September, 14 November.

WELLINGTON

Support and Connect group meets every six weeks on a Wednesday at 7.00pm-8.30pm: 29 July, 9 September, 21 October. Virtual support and Connect meeting held on the first Thursday of each month at 7pm via Zoom: 2 July, 6 August, 3 September, 1 October.

CHRISTCHURCH

Group meets on the last Tuesday of every month at 6pm-8pm: 30 June, 28 July, 25 August, 22 September, 27 October. Please note change of venue to Raraka Riccarton Centre.

DUNEDIN

Group meets every 6 weeks on a Tuesday at 7.30pm-8.30pm: 17 June, 29 July, 9 September, 21 October.

INVERCARGILL

Group meets on the 4th Wednesday of every month at 7pm-9pm: 24 June, 22 July, 26 August, 23 September, 28 October.

Support information

How can we help you?



Fertility NZ support contacts

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

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

dunedinsupport@fertilitynz.org.nz

Invercargill

invercargillsupport@fertilitynz.org.nz

Satellite coffee groups in North and South Auckland

For many years, Aucklanders have asked us for more localised support. So, we are delighted to now announce that satellite groups are starting in North and South Auckland. Both groups will be run by a pair of wonderful volunteers who bring experience from supporting people and facilitating other Fertility NZ groups in Auckland, together with their own journeys.

The North Shore group will be hosted by Keeley and Sheridan, and monthly meetings will begin in Takapuna during August. Helen and Kate will host the South Auckland group which will meet monthly in Pukekohe. During the week, Kate is our Support Coordinator and many of you may have already 'met' her via our Helpline.

Contact us as below for more information and join us for our first coffee meetings (no charge – hot drink provided by Fertility NZ). We look forward to welcoming you to our new friendly, casual and positive groups. People are always pleased they went!

North Shore: Keeley and Sheridan – northshoresupport@fertilitynz.org.nz

South Auckland (Pukekohe): Kate and Helen – support@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

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