

THE Dandelion

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

ECIAI

Anna Keogh shares her story - of grief, searching and hope - on the journey to parenthood via embryo donation.

Nothing can prepare you for news you would rather not be getting. The day my husband and I were called into the doctors office and told, quite bluntly, that there was a zero percent chance of us having our own genetic children (due to spermatogenic arrest azoospermia) was a day we will never forget. It was the day when everything turned a shade of grey.

From that day 10 years ago to now, a lot has shifted internally. It has been a journey of truly resurrecting hope inside of me.

Fast forward to a few months and tests later. Sitting across from the specialist we were eager to hear some good news - that we could do an IVF

cycle. But instead we were slid an information pack on sperm donation and told we could go on the waiting list but it would be up to two years. In shock, we turned the offer down and left feeling devastated. We flip-flopped over the next four years between being adamant we were not going to use a donor and then entertaining the idea that maybe it would be OK, but for us we could never fully reconcile the idea, as we felt we wanted a child that was both of 'ours'.

As a couple, our passion and desire has always been to leave a legacy. We believed this would be through our own children. Continued on page 4

NOVEMBER 2020

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Welcome Notes

Welcome to The Dandelion newsletter.

The year 2020 has certainly been a year of change. For those on a fertility journey, a sense of loss of control is common and COVID has really exacerbated that. Front of our minds has been how our community is coping and how we can best serve you during this time. If you haven't yet utilised our free resources and services - recordings of this year's information webinars, our helpline and support network, I warmly welcome you to do so.

As we commemorate Fertility NZ's 30th birthday, we have been reflecting on how the experience of infertility, and the landscape of whānau building in New Zealand, has evolved during that time. Embryo donation is a great example of this. Coined 'adoption with benefits', embryo donation is an option

which has grown in popularity over the last ten years. As success rates of fertility treatments improve over time, more people have embryos remaining after completing their families and these are the embryos that are used. Although embryo donation requires ethics committee approval, it is medically more simple than other options. Thank you to Anna for so generously sharing her story of embryo donation in this issue.

As a Charity, we rely on donations to continue our work. We are delighted to have been chosen as a charity partner of The Good Registry. The Good Registry's kaupapa is about giving for good, rather than creating waste and giving unnecessary gifts. Please consider The Good Registry as an option for staff Christmas presents, or

as a giving option to celebrate an IVF child (read more on page 7).

We are also excited to be part of The Collective yoghurt company's Chefs for Good programme, having been chosen by chef Sachie Nomura (see story next page). Try the delicious yoghurt in your supermarket, every purchase helps us!

Finally, look out for our video called "30 years of supporting Kiwis to become parents" on social and digital platforms during November (see story page 7). Thanks to the incredible people who told us about their journey and how we supported them, for the video.

Best wishes for a happy, healthy and balanced summer, wherever you are on your journey. Juanita Copeland – Chair

Delicious yoghurt and a great cause

Owner of the prestigious Sachie's Kitchen and one of New Zealand's most experienced Asian cuisine Chefs, Sachie Nomura, has joined forces with The Collective to create a gourmet probiotic yoghurt, with proceeds going to her chosen charity, Fertility NZ!

Sachie's new Vietnamese Coffee creation is inspired by her love of Asian flavours, bringing together the decadent flavours of authentic, sweet Vietnamese Coffee* with thick and creamy probiotic yoghurt. The launch of this new limited yoghurt comes as part of The Collective's 'Chefs for Good' series; an initiative that collaborates with leading Kiwi chefs.

"Fertility NZ is a charity that is very close to my heart as my husband and I have struggled with infertility. Through their support



and advice, we were able to start a family and for that we will always be incredibly grateful. It is hugely meaningful to me that we have this opportunity to give back to Fertility NZ through my passion for food creation. Now other Kiwis can also support the important work done by this charity simply by enjoying my Vietnamese Coffee yoghurt

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.



When considering how to mark Fertility NZ's 30th birthday, the answer quickly became obvious; we need people who have walked a fertility journey to share their stories, and how Fertility NZ helped them through that.

We are delighted - and moved - with the end product; a short video on social and digital platforms about the experience of infertility. The campaign also has a \$30,000 fundraising target

30 years of supporting Kiwis to become parents

through a dedicated Givealittle page, to help us continue our great work and meet the additional demands on our helpline and support post-COVID. Look out for the video on our website and Facebook page during November. Share it with your friends and family to help them understand what it's like to experience fertility challenges. If they want to help you in some way, encourage them to make a donation.

Thank you to the wonderful people who so generously shared their journey: Debbie, Gareth, Susan, Cassandra, Alan and Maddison. We'd also like to thank Sanele Chadwick for donating his time and expertise to produce this video.



by The Collective," says Sachie. Look for Vietnamese Coffee yoghurt in the yoghurt section at New World, Pak'nSave and Countdown.

*There is 3mg of caffeine per 100g serve of The Collective's Vietnamese Coffee yoghurt, compared to a single espresso or espresso-based drink, which contains 60-80mg.

Have you seen our video yet?

Our 30th birthday is about recognising all the mahi we have done over the last three decades. Thank you to everyone who has been, and is currently, part of our community. Fertility NZ is largely run on volunteer power and we are incredibly grateful to the hundreds of dedicated people who have donated their time and energy, with the hope of making one of life's toughest challenges just that little bit easier.

A VERY **SPECIAL** STORY

From page 1

We felt ripped off and angry and I became cold and hard inside. I withdrew from friendships, and could never pull myself together enough to attend baby showers or kids' birthday parties. I acted like I was 'handling' it, but if you saw me on my own, alone at home with my emotions, you'd know that I wasn't.

Although I was wrestling with not being able to have children, I still couldn't escape the fact that I wanted to be around them, so I took an opportunity to work with an organisation that went into primary schools teaching values, running camps and holiday programs.

For a couple of years I gave it my all and I loved being around so many kids. But in the background, this sadness would lurk. As hard as it was, I decided to resign from a perfect job because my pain had overcome me. I was angry, bitter, negative and didn't feel I was doing anyone any good by pretending.

I wrote a Facebook post explaining why I was leaving my job. It was honest and transparent and let everyone know exactly how I was feeling about not being able to have kids. Little did I know that this was a catalyst for THE. MOST. AMAZING. JOURNEY.

A courageous couple managed to do IVF, and subsequently have three gorgeous children as a result. They felt their family unit was complete, but they had the moral issue of still having embryos frozen. In New Zealand, your choices with leftover embryos (other than using them) are to discard them, or donate them to another couple.

What a hard decision to make! This couple, believing that their embryos were little lives who deserved to be given a chance felt that donation was their way of helping another family become realised, and so they were searching for the right couple.

Connecting with the heartache

"We felt ripped off and angry - I withdrew from friendships and could never pull myself together enough to attend baby showers or kids' birthday parties."

of infertility, they approached us and started a (very awkward, haha!) conversation about the possibility of us having their three 'frozen chosen'. It was an immediate connection and we were even amazed at the similarities we had in our beliefs, passions and talents. For the first time in this whole journey, we felt *peace* and even got excited. Hope arose in me again.

What followed that conversation was more than a year of more conversations, prayers, phone calls, counselling, paperwork, developing friendships, legal dealings and emotions. Oh, the emotions!

Surreal

It wasn't as easy and straightforward as we would have liked - our first ECART application was deferred but eventually, we got the "yes", our application to receive donor embryos had been approved!

The process of preparing for the embryo transfer involved blood tests, scans and medication, but was fairly



straightforward and the clinic staff were so encouraging and informative. The day we had our first embryo transfer was surreal. Ten days later, on Mother's Day 2017, we received news we never thought we would hear. We were going to be parents!

Tasia Belle Keogh (whose name means 'beautiful resurrection') was born on the 26th of January 2018 and

"We believe in the importance of a child knowing where they come from and how they fit in the world, so we will always share with our children their very special story."

has fitted into our family beautifully. She is the child we were meant to have and she resurrected my hope in good things! Her story is a miracle and is one we eagerly share with others. We have found the beautiful, sacrificial gift of an embryo awakens something inside of people, and we thank God that He chose us for this incredible journey.

Not for everyone

We acknowledge that using a donor embryo is not the right fit for everyone, as it brings with it (potential) relationship issues with the donor family and their children, as well the possibility for grief to pop up as you try and search for yourself in your child's face. For us, it put my husband and I on the same page in that there was no genetic connection to either of us, so we could both, side by side, embark on the journey of getting to know our child. In saying that – there is something to be said for nature vs nurture - but that is another story! Another baby girl, due November

2020 is the second of our 'frozen chosen' and we have one left in storage. Our second pregnancy has brought with it a large bleed due to a haematoma from 10 to 20 weeks which meant forced pelvic rest and lots of monitoring, but we now eagerly await her arrival and believe her story, too, is one to be celebrated and cherished.

We maintain a growing friendship with our donor family and their children dote on Tasia and feel proud to have her as their sister. We believe in the importance of a child knowing where they come from and how they fit in the world, so we will always share with our children their very special story.

Prospective recipients of donated Issues for people considering

Embryo donation has been described as 'adoption with benefits' and some countries even refer to it as 'embryo adoption'. Although the recipient parents have no genetic link to the child, a prospective mother can achieve a biological link through pregnancy, childbirth and breastfeeding. embryos must have embryo donation recommended by a fertility specialist as medically being an appropriate option for them to have a child. Embryo donation means that there could be full genetic siblings growing up in a maximum of two families (this includes the donor family). donating embryos include: their level of attachment to the embryos; reasons for wishing to donate versus discarding; relinquishment of control over the way that child would be raised; and the possible range of future relationships between children in the recipient and donor families.

Implications counselling is

essential for ensuring the best long-term outcome for all parties involved, especially the child(ren). A joint counselling session with donors and recipients is also a requirement for embryo donation in New Zealand, i.e. donors and recipients must meet. Embryo donation is a complex

process that requires caseby-case approval from the Ethics Committee on Assisted Reproductive Technology (ECART). There is a time commitment needed from all parties in this process, and a cost to potential recipients. ECART approval is required in all cases of embryo donation, even when it is a known donation between family members or friends.

If you would like to donate your

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Embryo Donation

embryo(s), you should notify your clinic who will then attempt to match you with people who are seeking donor embryos. You have the right to restrict the donation to certain groups, such as geographical area or family type. Clinic counsellors will be able to assist with further information and support.

Legal guidelines for embryo donation were updated on 1st September 2020. People who have embryos created with donor eggs, donor sperm, or both, can now donate them (consent of the original egg and/or sperm donor is required). Further, a donated embryo can now be used in conjunction with a surrogate (previously, to use a surrogate there had to be a genetic link to at least one of the intended parents of the child).

For further information, visit the Publications and Resources section of www.acart.health.govt.nz.

Search 'embryo donation' on www.fertilitynz.org.nz to find resources and guidance. From there, you can watch the recording of our 2020 webinar with an overview of the process plus stories from both donors and parents. Also, we welcome people considering embryo donation to join our online community, the Donor Conception & Surrogacy Network.

Search Facebook groups for 'donor conception surrogacy nz' (it's private, so only other members can see that you belong). Screening questions apply.

Finally, contact our free helpline on 0800 333 306 / support@fertilitynz.org.nz with any questions, or if we can help you explore whether embryo donation is right for you.



Dr Sonja Goedeke of Auckland University of Technology gives an overview of her recent research.

Should egg and sperm donors be paid?

Fertility treatment involving donor assisted conception has become more common in many countries and currently in New Zealand and Australia, about 5-10% of treatment cycles at fertility clinics involve donor gametes. In spite of these facts, people seeking treatment with donor gametes, be it with donor sperm or donor eggs, often find that it is not so easy to access gametes due to long waiting lists. There are many reasons that can explain long waiting lists with considerations about compensation being one of them.

In New Zealand and Australia we operate an altruistic system of donation, which means that while donors can generally be reimbursed for the expenses associated with their donation, they will not be paid fees over and above the costs they have incurred for providing their gametes or the service of donation.

To help with donor gamete shortages and long waiting lists some researchers have argued that we need to overtly pay donors of eggs and sperm over and above their reimbursement costs, but whether those affected by infertility, those working in the field or the public support this is largely unknown.

In our study, we surveyed 434 participants including fertility clinic patients and professionals, members of the public, and donors and recipients from across New Zealand and Australia. We asked them their views about support for different payment options for donors. Overwhelmingly, people supported reimbursement of expenses associated with the actual donation.

Our participants felt that donors should be reimbursed for their medical expenses, travel time, unpaid time away

from work relating to donating and any out-of-pocket expenses. Payment over and above reimbursement however, which would lead to donors financially profiting, received lower levels of support, even though some of our participants did regard payment as potentially necessary to increase the supply of donor eggs and sperm.

Recognition

We noted that even where participants supported payment, most recommended payment amounts that were quite similar to current reimbursement rates, especially for egg donors. Importantly, participants were also reluctant to move towards a commercial model similar to the one adopted in the USA. They were keen to retain donation as a form of giftgiving while at the same time wanting to ensure that donors were recognised for their efforts in some way.

The concept of paying gamete donors furthermore raised some specific concerns. In our study participants were concerned that if donors were paid, that this might attract 'the wrong type' of donor with questionable motives, such as individuals who were mainly financiallymotivated rather than motivated by caring and concern for others. They also worried that if donation became paid that donors, in attempts to be accepted into donation programmes, might not disclose important information such as medical or psychological histories or social issues that might be relevant for people born of donation.

These concerns are important to consider especially given that donorconceived offspring may have access

to identifying donor information when they turn 18, and that contemporary DNA testing reduces the possibility of anonymity. This means that the chances that donors and their recipients and donor-conceived offspring might have contact and even meet are increased, and consequently who the donor is as a person may be an important consideration.

Finally, our participants expressed a level of concern about the already-high costs of fertility treatment and that donor payment would increase the costs carried by intending parents.

Overall, those with personal experience of infertility and professionals held stronger concerns about donor payment, but concerns about payment influenced not only the views of these individuals towards using paid donors, but also prospective donors, who indeed indicated that they would be less likely to donate if they were paid. This suggests there is more to the gamete donation process than potential financial reward.

Ethical questions

Our study raises some interesting clinical and ethical questions for practice in New Zealand and Australia. Clearly, most participants in our study would prefer donation to remain altruistic but ways of optimising donor recruitment are important as current donor numbers may not be sufficient to meet the needs of patients requiring donor treatment.

This implies a need for us to carefully consider other ways in which people may be encouraged to donate, such as public education campaigns about the need for donors, and additional ways for us to recognise donors, such as enhanced clinical care. We hope to be able to research these areas in more depth in our future research studies - so watch this space!

Thank you to all those participants who took the time to take part in our survey and to share their views, and a big thank you also to FertilityNZ for advertising our study.

If you have any comments or suggestions, please feel free to get in touch: Dr Sonja Goedeke, sonja.goedeke@ aut.ac.nz

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 New Zealand spent a year developing the fertility-specific programme alongside YMCA and Pharmaco Ferring. Research

shows that lifestyle changes and even modest weight loss can improve the chance of conception; and this drove us to develop a safe solution for our community. Further, the condensed 10 week time frame is ideal during a timecritical journey. Jumpstart is fully customised to each participant and includes guidance for conditions such as Polycystic Ovarian Syndrome and Male Factor infertility as well as fertilityspecific nutrition advice. The initial pilot of

Jumpstart was interrupted

www.jumpstartprogramme.co.nz/fertility

fertility

Find us on The **Good Registry!**

Have you heard of The Good Registry? It's a gift website where 'caring people give kindness instead of stuff'. It's about reducing waste, eliminating unwanted gifts, and choosing instead to make donations for good causes like Fertility NZ!

There are two ways to engage with The Good Registry. You can set up a registry for an event like a wedding or perhaps a baby shower or birth of a much-wanted child. Instead of giving gifts, people find your registry and donate to good!

The Good Registry is also a great option for corporate giving. Even in a tough economic climate, employers can thank their employees with a \$10 gift card at the Good Registry; and the employee then logs on and chooses which charity, or charities, to donate their gift to.

Thank you for including us in your wonderful kaupapa, The Good Registry. We are excited about doing good together. We're here to hold the hands of Kiwis striving to become parents and The Good Registry will support us to do more!

We have been working hard to grow the support we offer to single women who are considering or have chosen to have a family with the help of donated sperm. We are delighted to announce that we now offer support and whanaungatanga in Christchurch, where Kim 6 weeks.

Meet our wonderful Single Women support volunteers:

by COVID, so a new Pilot programme will start 15th February 2021, 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. Register your interest now to optimise your fertility!





Single by chance mothers by choice

Rochelle had found herself single and with her fortieth birthday approaching, she knew she needed to act promptly and act alone. The imminent ticking of her biological clock forced her to rethink the 'fairy tale' ending. Rochelle is a proud single mother by choice to a beautiful donorconceived son.

Kim had always wanted to be a mum. Being single and approaching her fortieth birthday she realised time was not on her side and she needed to explore her options. Kim is now a single mother by choice to two gorgeous donor-conceived boys. Read Rochelle's story and find more guidance on www. fertilitynz.org.nz - choose 'donation and other options' and then 'single women'.

Contact us:

Choice

Rochelle: singlewomensupport@ fertilitynz.org.nz Find us on Facebook: **FNZ Single Mothers by**

Kim: singlewomensupportchch@ fertilitynz.org.nz Find us on Facebook: SMC Christchurch

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noticeboard

AUCKLAND

CASUAL COFFEE GROUP, MT EDEN

Group meets monthly on Wednesdays at 7pm. 18 November, 17 February 2021, 17 March.

CASUAL COFFEE GROUP, NORTH SHORE

Group meets monthly on Tuesdays at 7.30pm 17 November, 16 February 2021, 16 March

CASUAL COFFEE GROUP, PUKEKOHE

Group meets monthly on Mondays at 7.30pm. 2 November, 2 February 2021, 2 March.

FERTILITY SUPPORT SERIES

semi-structured course ideal for couples (spaces are limited). Resuming in 2021 – dates to be confirmed.

PREGNANT AFTER FERTILITY TREATMENT

Group meets monthly on sundays. 8 November, 14 Eebruary 2021, 7 March.

SECONDARY INFERTILITY

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

SINGLE MOTHERS BY CHOICE

Group meets on the last sunday of the month. 29 November, resuming February 2021. Please email for details: singlewomensupport@fertilitynz. org.nz

HAMILTON

Group meets every 3rd Saturday at 10am. 21 November, 20 February 2021, 20 March

Contact your local support Volunteers for details of group

meeting and any

questions.

TAURANGA

Group meets every two months on a saturday at 10.30am. 21 November, 27 February 2021

WELLINGTON

'Support and Connect' group meets every six weeks on a Wednesday. 11 November (AGM), 17 February 2021, 31 March. Virtual Support and Connect meeting held on the first Thursday of each month via Zoom. 5 November

CHRISTCHURCH

Group meets on the last Tuesday of every month 6–8pm. 24 November, 26 January 2021, 23 February.

SINGLE MOTHERS BY CHOICE

Group meets every 6 weeks on a Sunday. 8 November, resuming February 2021. Please email for details: singlewomensupportchch@ fertilitynz.org.nz

DUNEDIN

Group meets every 6 weeks on a Tuesday 7.30–8.30pm. 2 December, 16 February 2021

INVERCARGILL

Group meets on the 4th Wednesday of every month. 25 November, resuming February 2021. Please email for details: Invercargillsupport@fertilitynz. org.nz Support information



Fertility NZ support contacts

Auckland

- aucklandsupport@fertilitynz.org.nz (Fertility Support Series, Casual Coffee, Pregnant After Fertility Treatment)
- secondarysupport@fertilitynz.org.nz (Secondary Infertility)
- single women support @fertilitynz.org.nz

Hamilton

hamiltonsupport@fertilitynz.org.nz

Tauranga taurangasupport@fertilitynz.org.nz

Taranaki taranakisupport@fertilitynz.org.nz

Wellington wellingtonsupport@fertilitynz.org.nz

West Coast westcoastsupport@fertilitynz.org.nz

Christchurch

christchurchsupport@fertilitynz.org.nz singlewomensupportchch@fertilitynz. org.nz

Queenstown queenstownsupport@fertilitynz.org.nz

Dunedin dunedinsupport@fertilitynz.org.nz Invercargill

invercargillsupport@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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