

THE Dandelion

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

JULY 2018

WORLD'S **FIRST IVF BABY** TURNS 40

On 25th July, the world's first 'test tube' baby, Louise Brown, will celebrate her 40th birthday.





The highly anticipated birth of baby Louise was by planned caesarean section at Oldham General Hospital, UK, on 25th July 1978. Parents Lesley and John Brown had been trying to conceive for nine years, and sought the (then) experimental treatment, later to be known as In-vitro fertilisation, through Drs Robert Edwards and Patrick Steptoe. Dr Robert Edwards was later knighted and received the Nobel prize in medicine

for his work. The concept of life 'starting' outside the human body captured the imagination of the public (and of ethicists and religious leaders) in a way that is now hard to imagine, and had a huge impact on the road to reducing the stigma and silence accompanying infertility.

Louise Brown's sister Natalie, the world's fourth IVF baby, was the first

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Welcome **Notes**

Welcome to The Dandelion newsletter.

Research consistently demonstrates that New Zealanders have low levels of fertility awareness. Young New Zealanders, for example, predict the decline in fertility to occur much later than it does in reality. Another fact which troubles us is that young New Zealanders overestimate the success of fertility treatment. Whilst the wonder and science of IVF has helped to create millions of babies, it must be remembered that IVF is not a 'silver bullet' and by no means guarantees success.

Facts such as this underpin this year's Fertility Week campaign, 'Discover your chances'. We challenge all adults who are not yet trying-to-conceive, to discover their chances of achieving the family they desire and to be proactive in learning key facts about their fertility to enable planning and decision-making. We also look forward to seeing our trying-to-conceive community, both in

person and at our webinars, during Fertility Week, 24-30 September.

In line with our Fertility Week theme, this edition of *The Dandelion* looks at both the success and limitations of fertility treatment. During July, the world's first IVF baby turns 40 – and we reflect on the achievements of fertility treatment over the past 40 years. Also in this edition, we hear from Kathryn Grade whose journey did not result in the child she wished for. Kathryn looks back on her journey and her new status of 'living childfree'.

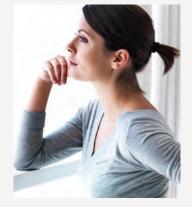
Fertility NZ exists to support you, and any feedback you have on the information, support and advocacy we provide is always welcome.

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

Best wishes Anita Killeen – President

Single Mums by Choice

Over the past years, we have seen an increase in the number of enquiries from single women considering 'going it alone'. Many of these women experience grief around the realisation that the family they dreamed about (or assumed) will not happen. However, there may also be a sense of empowerment over the decision to pursue single motherhood. Whether



you are considering building your family in this way, you are a single woman having difficulty conceiving, or you are already on this path, you are very welcome to join our Single Mums by Choice group, which meets monthly in Auckland. See the back page for dates and for more information, email Rochelle on singlemumsupport@fertilitynz.org.nz

Those 'going it alone' in other centres around NZ are very welcome to join the general support groups (for detail, see back page).

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

Our vision

FertilityNZ 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 and family-building are respected and valued.



Donor Conception support: you spoke, and we listened!

Fertility NZ exists to hold the hands of New Zealanders through their fertility journeys. We want to extend the support that we provide for our donor conceived (DC) community through providing specific information, and a platform for peer support.

So, earlier this year, we surveyed our members and followers on the types of support that would be of most value. Respondents were asked to rate their interest levels in six different support offerings. The most popular support offering was 'Helping parents' discussion with DC children (seminar format)', of which 78% of respondents were 'Reasonably interested' or 'Very interested'.

The second most popular support offering was 'Connecting with parents of other DC children', to which 73% of respondents were interested. Thirdly, 'Connecting DC children with each other' was of interest to 65% of respondents.

Of less interest were support offerings connecting sperm, egg and embryo donors with each other.

Thank you to everyone who took the time to respond. Over the coming months, we will be establishing a closed Facebook group for our Donor Conception community, and hosting a Webinar on 'Helping parents' discussion with donor conceived children'.

All FNZ support in the area of donor

conception is equally suited for people considering building their families through donor conception, and those who are already on that path. As the group grows, over time we would ideally like to organise annual or six-monthly gatherings in the main centres.

If you would like to be kept informed of our activities in this area, ensure that you are a member of Fertility New Zealand. Registration is free, at www.fertilitynz.org.nz/register. Select 'I would like to receive donor conception emails'.

We look forward to providing dedicated support in the growing area of donor conception.

First 'test tube' baby turns 40

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IVF baby to have her own child in 1999, conceived naturally. Louise Brown has subsequently given birth to two sons, both conceived naturally.

Since Louise Brown's birth, a further six million babies around the globe have been born following Assisted Reproductive Technology (ART). The past 40 years has seen ART progress in leaps and bounds and enable many different forms of whanau building. We urge our readers to remember, though, that IVF is not a 'silver bullet' and there are still many people who have undergone IVF and are involuntarily childless.

We would like to reflect on this milestone created by the Brown family, the late Sir Robert Edwards and Dr Patrick Steptoe. The technology pioneered by them has impacted the lives of so many people and created much-wanted families, around the world.

Happy birthday, Louise!

IVF: the NZ Timeline

- Late 1970's Ovulation induction programme set up by 'Mont' Liggins and a donor sperm programme set up by Professor Dennis Bonham. Both were at National Women's Hospital (NWH) in Auckland.
- 1983 Dr Freddie Graham established an IVF programme.
- 1984 New Zealand's first IVF baby, Amelia Bell, was born on 24 June.
- 1986 the waiting list for IVF at NWH, at the time the only programme in the country, was equivalent to 7 years' workload.
- **1986** The first embryos are frozen at NWH.
- 1990 The Auckland and Canterbury Infertility Societies merge to become Fertility New Zealand.
- 2004 The Human Reproductive Technology (HART) Act that provides for the regulation of procedures that assist with human reproduction was passed.



Louise Brown with her youngest son Aiden.

Now, around 2 percent of all babies born in New Zealand were conceived via Assisted Reproductive Technologies. Fertility NZ wishes to improve access to fertility treatment and will be lobbying the government for increased funding in 2019.

How I let go of the Baby Dream by Kathryn Grace

This is the story of my journey with fertility - or rather, infertility. It's not one of those fertility tales that inspires hope and promise of the long-awaited baby. It's not even one of those helpful blogs that let you know what it is really like to go through fertility treatments. It is just my story.

When I was young I often dreamed about what I would be when I grew up. The possibilities were exciting. I felt that I would do something but I just didn't know what. One thing I did know was that I wanted children – lots of them. Coming from a big catholic family and growing up around other big families, this was just standard. Why wouldn't I want that? Little did I know that life had other plans.

My husband and I met in London, just before my 30th birthday, and we hit it off. That time of our life was spent travelling, partying and generally living in the moment. We felt young and free there was plenty of time to settle down.

A few years later we moved back to New Zealand and settled into sensible jobs, worked hard and saved to purchase our first home. Soon after, we got cats and the transition into suburban life was almost complete. Next it was the wedding and then, of course, kids. We wanted children so much. Even though we were on the slightly older side, we were healthy and ready and believed it would just

happen - it was meant to be.

That belief kept us trying for 8 years. Those years of trying were long. When things didn't happen as we thought they would, we explored many avenues in an attempt to make it happen. I was going to get pregnant, and I just needed to figure out what was amiss. Specialists told us that there was no reason for the infertility and put us in that lonely "unexplained infertility' camp. They also explained that even though there was no reason for the infertility, the problem was with me. I was obviously broken and at fault!

Missing piece of the puzzle

We tried everything to get pregnant. I read and researched anything that I thought could help us. There were visits to doctors, specialists and alternative health practitioners. I thought if we just tried this treatment, or that approach, that it could be the missing piece of the puzzle and the answer to our dreams. Tests were undertaken. Scans were carried out. Blood tests done. Cycles were religiously recorded. Detoxes were

done to cleanse my body of the toxins I had consumed and prepare it for new life. Diets were changed. Alcohol was eliminated. Fertility herbs were taken. Fertility drugs were administered. I listened to lots of advice. I tried focusing on other goals. I even took a couple of months off work to de-stress and increase my chances of conceiving.

Despite all best intentions, the quest to start a family began to slowly suck away spontaneity and joy and overtake my life. It was hard for it not to when every day was marked with recording this and that to pinpoint the optimal time to try for a baby that month and every month was marked by the unmissable notification that I was not pregnant – again. With every month that came around, I felt more and more disappointed. That disappointment slowly became sadness. I felt like such a failure.

I wanted so much for us to have a baby and start our own family. I knew age was against me and it felt like a ticking time bomb that I couldn't get away from. Time was slipping away and this added to the pressure and my desperation.





Feeling the pressure

But the harder we tried, the harder it became. People stopped asking us when we were having children pretty quickly. It soon became the elephant in the room. The friends that did bravely broach the subject could sympathise but I often just felt worse after talking to them and trying to explain. They didn't understand what we were going through and they certainly didn't seem to understand the choices I was making. Mostly I just felt ashamed and that made it so hard to share.

I felt a lot of pressure to get pregnant (mostly from myself) and when it didn't

happen time after time, I felt utterly and totally hopeless. Infertility was not part of our plan! For some reason, I felt responsible for this "infertility". I was sure my husband thought that the fault lay with me (he didn't) and I felt so guilty. I desperately wanted to create a family together, to have children with my husband, and I felt incredibly sad that we couldn't. What was I doing wrong?

As more and more friends became pregnant and then pregnant again and then again, I felt like an outsider from the mother's club. I got pretty good at putting on the brave face when I heard the news that someone was having a

baby. I was always happy for them, but just sad for us.

The emotional roller coaster of trying and failing was exhausting. I constantly moved from hope and optimism to disappointment and grief and then back to hope. Trying to contain all those emotions is exhausting. Putting on the brave face only works for so long.

When we decided to try IVF it felt like the last chance and hope of a pregnancy. We'd never been able to conceive but somehow I still had a belief that it would happen. Even knowing the success rate of IVF, I had a renewed sense of optimism.

"I remember crying until I just couldn't cry anymore. It was equally hard to see how upset and devastated my husband was. I felt completely empty. Was this all really worth it?"

Everything went so well and when I got the call to say we were having a baby I went into a state of shock. I could hardly believe that we were actually going to be parents after all this time. Shock quickly made way for joy and I felt on top of the world. Being pregnant seemed so natural and I was remarkably confident things would go well. I felt like I could now start getting on with my life. We started sharing the news with family and close friends. Everyone was thrilled for us. I knew our baby's name. It wasn't a name we had ever considered when we used to talk about baby names all those years earlier but I just knew. Her name was Natalie.

We found out the baby stopped growing at seven weeks. The grief we felt was immense. I remember crying until I just couldn't cry anymore. It was equally hard to see how upset and devastated my husband was. I felt completely empty. Was this all really worth it?

This was the point I decided to jump off the roller coaster and let go. What I had always steadfastly believed would happen, just didn't. We had invested thousands of dollars, hours and hours of treatments, and years of our life. There had to be something else better than this but giving up our dream when we had got so close seemed crazy.

Making that decision gave me such relief. I was released from the neverending pursuit and suddenly I felt a sense of possibility again. I understood that there were other potentials and opportunities out there for me. I could take back control of my life.

The ease at which I adjusted once I had made my decision seemed to concern people around me – and I was surprised myself. This thing I had so desperately desired for years and that

was in the fabric of everything I did, in my very psyche, I let go. It wasn't a decision I took lightly and I am forever grateful to a wonderful support person who helped guide me to this decision. Once made, I didn't even so much as glance back. It just felt so good, so right and that was something I hadn't felt in such a long time. I knew it was the right decision. It was time to accept that this wasn't the path and move on to something else. People didn't seem to understand why I would give up when the possibility was close. "Had we considered adoption?" they would gently inquire as though sharing with us some amazing solution that had never occurred to us.

Emotional journey

Those years have been a journey of immense emotion. Emotions of grief, disappointment, hope, sadness, isolation, and even shame. Emotions so strong and persistent that it has taken a strength to contain them, for fear they would consume me. I was so focused in my goal that I never considered that there may be other paths. I was so sure we would have a family and it was just a matter of being strong and keep believing. I now know that sometimes having a baby isn't just a decision you make.

"What I needed most was to not feel alone. I needed people who really understood what I was going through, that I felt safe enough with to share how I felt."

This journey has taught me so much. It demanded that I take care of myself physically, mentally and spiritually. I know how to listen to myself and make choices that feel right to me – something I had never been particularly good at. I have learnt to be vulnerable. Above all, I have learnt acceptance. I have learnt to trust.

Not having children doesn't make me a failure. It doesn't make me less of a woman. I am never going to be a mother or a grandmother and experience what that feels like and I am OK with that. I am a wife, a daughter, a sister, a niece, an aunty, a cousin, a friend – and so much more. I understand that there are many ways to create and nurture, and many ways to be a woman. I love my life, and now that I am not having children, I feel so many other opportunities and potentials open up again.

While I am eternally grateful for where I am, it is difficult not to look back and wish I had just let go much sooner. That I had replaced that determined belief that it was going to happen with a gentler trust that whatever happens is OK and just got on with life. I relied too much on Hope. I expected too much from her when what would have served me more was Trust. Rather than Faith I needed Truth. I know now that the way to truth is through awareness and acceptance.

Support

Infertility felt so isolating for me and looking back I can see what a big impact it had on me emotionally and as well as on my relationships. It's not that I'm an emotional person – I just struggled to acknowledge and share what I was really feeling.

What I needed most on my journey was to not feel alone. I needed people who really understood what I was going through and that I felt safe enough with to share how I felt. Who supported me and the decisions I made, not because they thought the decisions were the right ones, but because I did.

The support that FNZ provides would have really helped if I had known about it. I needed gentle support from people who had similar experiences and could really understand what I was experiencing. I needed to be with other people who saw fertility as more than a medical issue, more than something that needs fixing and who had an openminded approach.

My experiences have led me to a place where I can support other women trying to conceive. I want women to feel OK no matter where they are on their fertility journey.



Campaign set to challenge Kiwis

24th-30th September 2018

New Zealanders have low levels of fertility awareness and 'Fertility Week: Discover your chances' aims to start the discussion and get people thinking ahead about their fertility.

The Discover your Chances campaign will centre around an interactive quiz which assesses fertility awareness and provides guidance on knowledge and/ or help needed. The quiz aims to reach people who are early in their journey, or not yet trying-to-conceive, and give them the right information to start planning for their future family.

Discover your Chances will also include in-depth information for our trying-to-conceive community, via the Fertility Week website, Webinars and in-person events around the country.

During Fertility Week, look out for

- www.fertilityweek.org.nz the hub of Fertility Week
- interactive quiz, available via social media and www.fertilityweek.org.nz
- fertility journeys as told by our members
- information events held within our support centres
- a series of information webinars held throughout the week at 8pm
- printed material to raise awareness of the campaign





- a series of short information videos for social media and the Fertility Week website (new activity)
- media engagement including social media
- promotion by NZ celebrities
- regional and national advertising

We always love connecting with our community during Fertility Week. We look forward to seeing you at our in-person events and webinars, all of which have leading guest speakers.

If you are not yet a member of Fertility NZ, join up today at www. fertilitynz.org.nz/register to receive information on Fertility Week.

See you September 24-30th!

promote Fertility Week, we can post you a few postcards and flyers for your local noticeboards (e.g. GP. library, shops).

Email Rebecca on support@fertilitynz.org. nz if you can help in this (or any other) way.

We are always very grateful for any help!



noticeboard

Support Group Dates

AUCKLAND: FERTILITY SUPPORT SERIES

Tuesdays 16th, 23rd, 30th October

AUCKLAND: PREGNANT AFTER FERTILITY TREATMENT

Sunday 1st July Sunday 5th August Sunday 2nd September Sunday 7th October Sunday 4th November

AUCKLAND: CASUAL COFFEE

Wednesday 18th July Wednesday 15th August Wednesday 19th September Wednesday 17th Oct Wednesday 21st Nov

AUCKLAND: SECONDARY INFERTILITY

Sunday 29th July
Sunday 26th August
Sunday 30th September
Sunday 28th October
Sunday 25th November
Sunday 16th December

AUCKLAND: SINGLE MOTHERS BY CHOICE

Sunday 22nd July Sunday 26th August Sunday 30th September Sunday 28th October

HAMILTON

Saturday 21st July Saturday 18th August Saturday 15th September Saturday 20th October Saturday 17th November

HAWKES BAY

Sunday 19th August Sunday 21st October Sunday 18th November

WELLINGTON

Tues 18th September Tues 30th October

CHRISTCHURCH

Tuesday 24th July Tuesday 28th August Tuesday 25th September Tuesday 23rd October Tuesday 27th November

DUNEDIN

Tuesday 3rd July Tuesday 7th August Tuesday 2nd October Tuesday 6th November

INVERCARGILL

Friday 6th July Wednesday 15th August Wednesday 12th September Thursday 11th October

Stay tuned for a **Fertility Week** (24-30 September) event near you. Email your local representative (right) or register at www.fertilitynz.org.nz/register

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

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