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THE Dandelion

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

NOVEMBER 2015

Redefining FAMILY



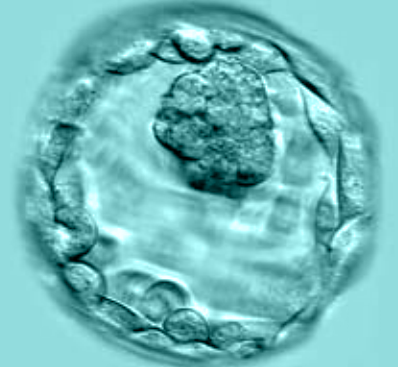
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REDEFINING FAMILY: Growing Families Through Adoption, Donor Conception and Surrogacy

Wednesday 13 - Thursday 14 January 2016

Hosted by AUT University

Fertility NZ is excited about this upcoming consumer conference which encompasses adoption, donor conception and surrogacy. It is the first conference of its kind in New Zealand – focussing on ‘alternative’ forms of family building.

For those who want to be fully informed on the social, emotional and legal aspects of these forms of family building, *Redefining Family* will help you with your

decision making. If you already have a child through adoption, donor conception or surrogacy, this conference will support your family going forward.

The *Redefining Family* conference is an opportunity to learn from some world renowned researchers and experts, who are in Auckland for an international research conference.

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menevit
DESIGNED FOR MALE FERTILITY



elevit

fertility
NEW ZEALAND



Welcome Notes

Welcome to this tenth edition of *The Dandelion* newsletter from Fertility NZ.

This is the tenth edition of *The Dandelion* newsletter, so an apt time to reflect on it. *The Dandelion* is our regular communication channel with our Members (all of whom receive *The Dandelion* via email) and others on their fertility journey.

Around a year ago, we dramatically increased the printing volumes to allow fertility clinics to provide *The Dandelion* to each of their patients. We are always grateful to our supporters who enable us to provide *The Dandelion* (as well as Membership of Fertility NZ) free-of-charge.

For those of you considering adoption, donor conception or surrogacy as family building options – or already have children through these – you may wish to attend the Redefining Family conference on

13–14 January in Auckland, hosted by AUT University.

Our network of support groups continues to grow. There is now an FNZ group in Taranaki which meets regularly. We also have a support person in Nelson who offers one-on-one support over coffee. See the back page for contact details of the support group nearest to you.

In this edition you will find two quite different stories from our Members. Laura shares her story of battling severe endometriosis as a teenager and now facing a future without children. Laura was lucky to have the support of her mother who had experienced endometriosis, however her friends' 'advice' was ill-informed and somewhat dangerous. Endometriosis was one of the

feature topics of Fertility Week this year – we encourage young women to learn about their fertility and seek help if they have any 'warning signs'.

Nicki also shares her experience of Unexplained Infertility, which was featured in Fertility Week this year. We are lucky to have Nicki as one of our volunteer Contact Group facilitators in Auckland.

We would love to hear your feedback on *The Dandelion*, and on the support Fertility NZ provides. 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.

Cheers

Nigel McKerras – President

About Fertility New Zealand

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

Fertility NZ was founded in 1990 and is a registered charity. It operates on a national level and much of its work is undertaken by dedicated volunteers. Fertility NZ provides assistance for people with fertility issues through the following channels:

- **Support** A network of regular support gatherings, workshops and contact groups throughout the country; an 0800 line and email address for enquiries, and infertility forums on our website where Members can provide support to one another.
- **Information** Fertility NZ's website www.fertilitynz.org.nz is the focal point of information; informative fact sheet brochures are available for Members and through Clinics; regular publication of *The Dandelion* newsletter and email updates to Members; conferences and

information events.

- **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.

Joining Fertility NZ

Are you a member of Fertility NZ? Registration is free-of-charge and can be done online through the Support section of our website.

Benefits of Membership include:

- We'll keep you informed of information events and support groups in your area (if you elect to receive these emails from us)
- You receive Updates from us including *The Dandelion* newsletter (if you elect to receive updates)
- Ability to participate in the Forums on our website
- You support all the valuable work we do for all New Zealanders experiencing fertility issues. We represent the voice of NZers impacted by infertility – and the more members we have, the stronger our voice.

Redefining family

◀ From page 1

Three plenary sessions are planned for *Redefining Family* that will interest attendees from across the different family contexts.

1. Redefining family in the modern world. This session considers trends in family formation, with emphasis on new family forms that separate the once combined biological, genetic and social parenting, including adoption, donor conception, surrogacy, foster care, kinship care and whāngai.

2. The socio-emotional issues in non-traditional families. This session looks at the developmental trajectory common in many of these alternative family forms, with a particular focus on children's and parents' experiences.

3. The legal processes involved in non-traditional families. This final session considers the legal frameworks for each family type, and looks at the challenges and barriers that must be negotiated in forming families via surrogacy, donor conception and adoption.

These will be followed by a panel session on the last day where leading researchers, lawyers and practitioners from the three domains will take questions from the audience.

Speakers include: Claire Achmad, Doctoral candidate, Dept of Child Rights, University of Leiden, The Netherlands; Dr Jane Aronson, Worldwide Orphans Foundation, USA; Kate Bourne, Victorian Assisted Reproductive Treatment Authority, Australia; Dr Dana Johnson, Division of Global Paediatrics, University of Minnesota, USA; Dr Gabriela Misca, Dept of Psychology, Worcester University, UK; Wendy Hawke, Executive Director ICANZ, New Zealand.

For up-to-date information visit www.redefiningfamilyconference.co.nz or email info@redefiningfamilyconference.co.nz

Important lessons from our fertility journey



Nicki McClintock reflects on the journey she and husband Dan shared.

Daniel and I had been married 2 years when we started trying for a baby. I was 27 and Daniel 29 – we didn't think our ages would be a problem. Both of us have always been lucky enough to have brilliant health, and after all – my mum had me at 25 and got pregnant the first month she tried. Although I was realistic and knew that after years of contraception, it might be a while before anything happened. We were OK with that... initially. On reflection, probably too accepting and with hindsight I kicked myself for waiting so long to take action. For about 2 years

we weren't stressing, but had no luck. We saw a specialist gynaecologist as my 'big 30' crept closer to see what he recommended. We'd begun wondering – was something wrong?

Basically we were told to keep doing what we were doing for another 6 months – but this time, try a little harder, take note of dates etc, and by the way – don't just have sex when you think you're ovulating, as it could happen any time of the month. Armed with more instructions (for something that should be pretty simple), off we went for another 6 months or so. Still no luck.

So, back to the specialist who sent us for a few tests – all normal. My ovarian reserve was a little low for my age,

After 7 years of trying, we went into our first IVF cycle. All our hopes were pinned on this last resort so when the cycle failed I completely lost it!



Above: Dan and Nicki with baby Joshua, and above left: Nicki awaits yet another clinic treatment.

◀ but nothing that should stop us. Dan's sperm count was fine. So, because time had been ticking away, we decided to go ahead with 6 months of Clomiphene to stimulate my ovulation. Half way through the treatment, we took a break as the constant 'fertility focus' had started to get me down. Daily thinking about getting pregnant – either taking a pill, booking an appointment, being prodded / scanned or being told when to go forth and procreate left little brain space for much else. I think this is when it started to break me... slowly but surely. We finished the treatment with an increased Clomiphene dose. Still no luck.

Putting life on hold

I'd been avoiding considering a full blown IVF procedure as firstly, I really didn't think it would come to that, things like that don't happen to me! And secondly, I had built IVF treatment up in my head to be such a big deal (far worse than it actually was in the end). But the time had come – I was 32 and had been trying for 5 years when we finally

saw a fertility clinic. More tests showed that although sperm count was OK, the motility was pretty average – but again, that should not have prevented a pregnancy after all that time trying. I had some cervical polyps removed – they weren't a likely problem either but we whipped them out 'just in case'.

Although I'm sure it's terrible being told you have a known fertility issue, not having a diagnosis to work with or a problem to address whilst being consistently told that nothing's wrong was more than frustrating – it was doing my head in. The not knowing and putting life on hold had gotten to the both of us.

Eventually after 7 years of trying, we went into our first IVF (ICSI) cycle with a good degree of hope. We'd ruled out everything we could – surely this would work. All our hopes were pinned on this last resort option. So when the cycle failed I completely lost it! And we

didn't even have any eggs to spare. As if to rub salt in my wounds, two close friends fell pregnant at the exact time our cycle failed. I was unable to speak to them for some time, let alone be happy for them. Severe depression hit me with full force, but sadly went undiagnosed so it was another 2 years before I finally remembered what it felt like to be happy again. The fertility journey had consumed me. Normally outgoing, chatty, and approachable, I became quiet, withdrawn, and moody.

Nobody understood

At work and socially, I avoided any and all interactions I could, but nobody understood. No-one really gets it unless they've experienced it. My self-imposed isolation was a form of protection, but looking back I should have sought out others in the same situation for support. I wish I had been brave enough. Thanks to my husband, some counselling helped me realise that my feelings were valid, but still I was definitely not OK.

All I could do was throw myself into another round of IVF. We braced

ourselves for another disappointment, but surprisingly this time we had luck. An actual positive result – I could not believe it. After finding it impossible to conceive, I had a pregnancy that was pretty much problem free – but I could not enjoy it. After so many years of trying to balance hope with reality, and knowing disappointment oh so well – I could not allow myself to believe this, as I knew I couldn't handle the heartbreak should anything go wrong. So – no baby-shower, no real acknowledgement as I remained in 'self-protection' mode all the way until I was induced at 39 weeks. Only once Joshua was born was it finally real.

Important lessons

Apart from my son, two very important (and positive) lessons have come out of this experience.

1. I've learnt I'm not invincible and shouldn't try to be 'cause no-one else expects it. Get help when you need it.
2. My husband is likely the best husband in the world – living with my

My depression was a nightmare for Dan but with his loving care and enduring patience our relationship grew ever stronger.

depression was an absolute nightmare for him. But thanks to his loving care, enduring patience and strong but silent strength – our relationship grew ever stronger as I realised he was more than up to the task of supporting me when I needed it most. It gave me great confidence for our future – whether that was to be with or without a child. Ladies, please value and include your men. We need them more than we like to think.

To anyone else with unexplained infertility, the waiting is so hard and you feel so alone – but you are definitely not. Try to find people you can talk to about it, there are many more in the same boat than you realise, and support is available.

PGD with PGS now available in New Zealand

If you're about to undergo IVF, you may have heard of Preimplantation Genetic Screening (PGS). PGS is a tool which can be used in an IVF cycle to assist in the selection of the embryo which has the best chance of progressing to a baby. It does so by helping to identify embryos with an abnormal number of chromosomes, which cannot give rise to a normal pregnancy.

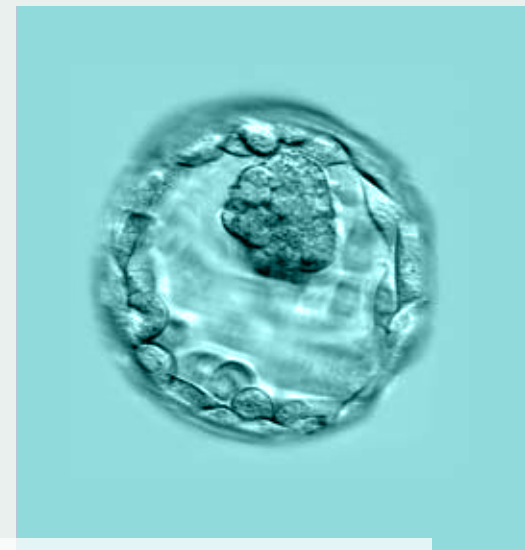
PGS has been available to New Zealand IVF patients for a number of years. The samples have been sent to laboratories in Australia for the screening. Fertility Associates is now offering New Zealand based laboratory analysis, which has the effect of reducing the cost of the service.

PGS may be suitable for:

- Women who have had recurrent miscarriages or lack of implantation, i.e 4 or more embryos transferred without a pregnancy.
- Women aged 36 and older, as the chance of an embryo having the wrong number of chromosomes increases after 36.

People who have several good quality, normal-looking embryos could also consider PGS, in order to provide better embryo selection. PGS can also be used by patients who have embryos stored from previous IVF cycles or have a large number of blastocysts created. PGS can be combined with PGD (Preimplantation Genetic Diagnosis) for specific gene defects, but there may be some limitations depending on the circumstances.

It is important to note that PGS does not increase the overall chance of a baby from an IVF cycle – the embryos are the same, whether or not PGS is used. However, PGS offers much better embryo selection and identifies embryos that have no chance of normal pregnancy. Cycles which use PGS have a lower chance



PGS does not increase the overall chance of a baby from an IVF cycle – the embryos are the same, whether or not PGS is used, but PGS offers better embryo selection.

of miscarriage because embryos with chromosomal number abnormalities are not transferred.

All PGS is privately funded – making it an 'optional extra' on top of publically or privately funded IVF cycles. Currently, the NZ based PGS service is only available at Fertility Associates clinics, with egg collection and embryo biopsy being done in Auckland, Wellington and Christchurch. If you live in the Hamilton or Dunedin regions, the biopsied embryos can be transported to Hamilton or Dunedin for embryo transfer locally. Other NZ clinics also offer PGS, via their Australian laboratory partners.

My private battle

Laura Thomas bravely shares her journey of severe endometriosis, polycystic ovarian syndrome and now, facing a future without biological children.

I started taking the contraceptive pill when I was 15. I soon came to the realisation that if you missed the 'sugar pills' and just continued to take the regular pills you would skip your monthly visitor. A year rolled around and by that time this little trick I had learned no longer worked. I asked my friends about it and they merely shrugged it off. We were young and didn't know much about the female body, so how were we to know any better. They suggested if I were to do it for too long then it would lose its effect and that's why I was now having these symptoms, which could seem semi logical.

At this stage I thought it was typical to bleed whilst regularly taking your pills – I would be keeled over in gut wrenching pain on the floor, unable to move but again thought this was standard amongst women. It occurred to me that it may be time to tell mum. She booked me in to her gynaecologist (the now late) Mr John Doig. I could not speak more highly of this man and how amiable and caring he was – but I shall digress – he discovered I had endometriosis and needed to have an operation. This news wasn't so bad, I thought to myself. More fool me, but naivety can be bliss for a time. Most people will have surgery in their lives and once this is done I will be right as rain.

I woke up in recovery after my surgery, John came and held my hand and told me I had Stage Four Endometriosis. I knew this was not good news however I did not grasp until later just how detrimental it was having the disease at the most advanced stage so young in life.

The next two years were similar to a miasma. I was in and out of the gynaecologist's office. I had a total of three gynaecological endoscopic

surgeries. My main memories were of being curled up in a ball on the floor unable to move some mornings trying to get ready for school, being so exasperated that I just could not muster the strength to get up. At one point there was no reprieve, I was bleeding every single day for 10 months straight. This was not minor or the normal amounts either, it was very cumbersome. What that does to your health and body is indescribable.

One day when I was at school with all of my friends, we were in the library for one of our classes. One of the girls, who I considered to be my close friend at the time, voiced her opinion on how I was absent quite a bit but I always made good grades and it wasn't fair. I slowly distanced myself from her after that. My mother never knew how often I was absent from school in the mornings, I was too ashamed to tell her. I would forge my own notes as I didn't want to look weak.

I graduated high school and got U.E. I knew exactly what I wanted to do with my life, I wanted to become a Clinical Psychologist. However, in the way of that would be one of those days that will never leave me.

Maybe I was feeling brave or auspicious that day I'm not too sure. Be that as it may I hadn't been bleeding for two days and was feeling fortunate. I was in PSYC106 lecture then got up to leave, walked down the stairs, a hot flush washed over me then it felt like I had haemorrhaged out of my body.

I ran to the toilet, locked myself in the bathroom, pulled myself together and cleaned away the river and trail of blood as best I could. Without flinching I rang my mother and told her to book me into the gynaecologist as I could not live like this for a moment longer. I knew precisely what I was going to do.

My gynaecologist was very supportive

of my decision to have a hysterectomy as there was no cure for what I had and I had endured the suffering for long enough, my case was just too extreme. We had tried drugs, we had tried a device, we had tried operations and nothing slowed it down. Each time it came back harder with a vengeance.

As I was the first woman in New Zealand of my age to have this surgery for this reason I had to be signed off by another gynaecologist who asked me a variety of questions like a psychiatrist would, to make sure I was of sound mind to make this decision. It was a little overwhelming; it felt like the Spanish inquisition.

I still remember all of her baby photos she had hanging on the wall almost as if they were there to taunt or test me, although I'm sure that was not the case. She posed the idea of trying to conceive with my partner within the next few months then getting the surgery there after as it would be my only chance to conceive if I could conceive.

Without flinching I said no, I need to do this for my own quality of life – I am at a point in my life where I could not support a child the way I dream of raising one. After a two hour session that I was signed off by all the appropriate people and in a few months in for surgery with two gynaecologists operating on me. It put me off University and my part time job for 6 weeks. It was the most intolerable pain I have ever felt, the type of pain that makes your body reject every movement, sound, drug and breath because of it. I thank my lucky stars I will never have to experience that again.

I would have not got through it if not for my family, my partner and best friend at the time. A support network is imperative.

The hardest part is having to tell your partner that it's not just a chance that you may be infertile or don't want to have children but there is 100% no chance you will bear a child.

It would be nice to think that this was the end of my story, yet unfortunately by age 21 I was back in surgery having my ovaries out. They were polycystic and poisoning my body so there was no point in trying to preserve them. It all began to wash over me when I was half sitting in my hospital bed, half crouched over my bed riled in pain, vomiting my guts out with no one else around, exactly the extent of what I was going through.

After that point I changed. I was more taciturn. I distanced myself from people, it was almost like a switch flicked off / the light went out. It hasn't come back on since.

The hardest part is exploring new relationships and having to tell your potential partner that you're infertile. Not just a chance that you may be infertile or don't want to have children but there is 100% no chance you will bear your own child. It is the make or break part. It is a huge relief if they accept you for who you are, but there is always that fear in the back of your mind that one day they will come to their senses and leave because of it.

When I told the man who is now my fiancé, he replied "I doesn't matter that you can't have children. I love you and want to be with you. I will do anything to try and get us a child later on in life". I know that he would make a fantastic father – maybe one day, a miracle will happen for us.

I have never shared my side of the story before, always kept it hidden deep down inside of me. A big part of the reason for this was because I was raised by a woman who went through the same medical issues. Some would think this would make it better. It did not. Her issues occurred after she had given birth to me so when I look at it the



**Laura and Johnny:
building a positive
future together.**

situation it is incomparable. Yet I was reminded how she had experienced it all before and was not impaired by it. This made me feel like I could show no perturbation towards the matter.

Later in life when I have broached the subject of children I am promptly reminded it is too hard to adopt children in this country. Even little fleeting comments like "lucky you can't bear children" cut to the bone when I know I shouldn't let them.

Now I can appreciate just how important it is for people to know that it does need to be talked about and shared. Whether it is couples facing infertility issues or young girls/women facing endometriosis, whatever your

issue may be. If it is not dealt with face on and you do not surround yourself with a support network and allow yourself time to lament – and I mean properly grieve in your own way even if you have to lock you self away in a room to do it. Unlike myself who has bottled every little emotion up. If as an individual we don't take the time to do this we lose a part of ourselves and it will be a part that I personally know I will never get back.

I have lost a lot of opportunities in my life, given up a lot and taken a lot of people for granted so far for lack of emotion I no longer have. Take it from a woman who has travelled the road and feels less like a woman because of it.

President's note:

Although not a trying-to-conceive journey, Laura's story is a raw and touching one and I'm sure that most of us can relate to it in some way. It is a reminder that journeys do not always result in children. It is important to keep hope alive and be positive, but also to realise (particularly for those who have had a long / significant journey already) that a positive outcome is not guaranteed. There are support networks for people coming to the end of their fertility journey – touch base with us if you are interested. Also, watch the 'Beyond Childlessness' video on our website. For those still in their fertility journey – research consistently demonstrates significant emotional and physical benefits of in-person support. Check out the back page for your nearest support / coffee group run by our network of fantastic volunteers who have 'been there'.

noticeboard



Support
Group
Dates

**AUCKLAND,
SECONDARY INFERTILITY**
Saturday 21 November
Sat 19 December
Sat 30 January
Sat 27 February

HAWKES BAY
Sunday 15 November
Sunday 17 January

CHRISTCHURCH
Tuesday 24 November
Tuesday 26 January
Tuesday 23 February

**AUCKLAND,
CASUAL COFFEE GROUP**
Tuesday 20 October
Tuesday 17 November
Tuesday 19 January
Tuesday 16 February

TARANAKI
Wednesday 11 November
Wednesday 9 December
Monday 11 January
Wednesday 10 February

WELLINGTON
Wednesday 4 November
Wednesday 4 February

DUNEDIN
Tuesday 3 November
Tuesday 1 December
Tuesday 12 January
Tuesday 2 February

Taranaki Support Group

There is a Taranaki support group made up of people who all understand firsthand the heartache of infertility and the ups and downs of fertility treatment. We meet in the evening on the second Wednesday of every month in a private room at the Ugly Duck, Fitzroy. New members (both women and men) are always welcome. All of us are at different stages in the journey – join us and gain support, knowledge, hope and friendship. To come along, or if you have any questions, please contact Katie or Michelle, email taranakisupport@fertilitynz.org.nz

Local information

How can we help you
in your area?

Fertility NZ Local Groups

Auckland

aucklandsupport@fertilitynz.org.nz
secondarysupport@fertilitynz.org.nz
(secondary infertility)

Casual Coffee Group (Auckland)
casualcoffeegroup@gmail.com

Hamilton

hamiltonsupport@fertilitynz.org.nz

Tauranga

taurangasupport@fertilitynz.org.nz

Gisborne

gisbornesupport@fertilitynz.org.nz

Hawke's Bay

hawkesbaysupport@fertilitynz.org.nz

Taranaki

taranakisupport@fertilitynz.org.nz

Wellington

wellingtonsupport@fertilitynz.org.nz

Nelson

nelsonsupport@fertilitynz.org.nz

Christchurch

christchurchsupport@fertilitynz.org.nz

Timaru

timarusupport@fertilitynz.org.nz

Central Otago

centralotagosupport@fertilitynz.org.nz

Dunedin

dunedin-support@fertilitynz.org.nz

Donor Conception

donorconception@fertilitynz.org.nz

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