

## THE Dandelion

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

### Fertility Week 2017 FOR ALL KIWIS!

It's a wrap! Fertility Week 2017 is officially over, and the campaign reached more New Zealanders than ever before.

With one in four New Zealanders experiencing infertility during their lifetime, we view our annual public awareness campaign as crucially important, both for people going through infertility and for those who may be affected in the future.

Fertility Week: How Kiwis Make Babies comprised three main streams of information: Making Babies DIY, Making Babies with Help, and Making Babies with Donors and Surrogates. The campaign aimed to provide

information and guidance for people planning for children in their future. through to experiencing subfertility and considering different ways to build their families. In addition, the campaign aimed to reflect different ways that Kiwis build families.

During Fertility Week, there were information events held in Dunedin, Christchurch, Nelson, Wellington, Hamilton and Auckland. All had guest speakers, and some events also had

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#### Welcome **Notes**

Welcome to The Dandelion newsletter.

It is with great pleasure that I write my first President's column. I was elected to the President role at November's AGM, after serving on Fertility NZ's Executive Committee for the last five years. I am a lawyer and an experienced governance professional who also brings a consumer perspective to the President's role. We also have several new people on the Executive Committee - details can be found below. Sadly, we say farewell to our outgoing President Nigel McKerras who served on Fertility New Zealand's Executive Committee for nine years. Our sincere thanks go to Nigel for his exceptional service and dedication to the work of Fertility New Zealand.

For those of you who are new readers, *The Dandelion* is the main communication medium we have with our Members and other New Zealanders experiencing fertility issues.

Thanks to the efforts of around 50 volunteers and more than 10 supporting organisations, Fertility Week: How Kiwis Make Babies was a resounding success. The Fertility Week website and our Facebook page reached twice as many New

Zealanders as previous campaigns. We were delighted to meet many of you in person at our events and virtually during the Webinars. It's our privilege to provide information and support to all New Zealanders through this campaign and we look forward to growing our success in future years.

Thanks to a wonderful network of dedicated volunteers, we have regular support groups running throughout the country. Invercargill is our newest support hub, and facilitators Aimee and Amy would love to meet you there. Our support groups are a safe space to gain support and connect with others 'in the same boat'. New people are always welcome. Turn to the back page for a group or event nearest you.

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

#### Fertility NZ's Executive Committee

Fertility NZ is governed by an Executive Committee. Our current Executive Committee, which was elected at our AGM in November, is listed below. We welcome our four new office holders!

Anita Killeen – President Juanita Copeland – Vice President / Christchurch Regional Representative Lisa Miller – Treasurer Janet Parker – Secretary

Corporate / Medical Members: Jo Barnett, John Peek Regional Representative: Karina Wong (Auckland)

General / Consumer Members: Jo Catty, K-J Dillon, Megan Kitchener, Gemma McGarry

#### 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.



#### Fertility Week 2017 FOR ALL KIWIS!

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our Members sharing their stories. The series of five live webinars with Q&A were also very successful. If you missed the webinars, fix yourself a hot drink and watch the recordings on www.fertilityweek.org.nz. Our Facebook page (Fertility New Zealand) also features videos from the information events which were live streamed.

The information contained within Fertility Week was specifically developed by a team of experts (medical, academic and complementary) provides comprehensive yet practical guidance for all New Zealanders wanting to learn more about their fertility. Along with the personal fertility stories which were shared for the campaign, Fertility Week: How Kiwis Make Babies was truly by New Zealanders, for New Zealanders!





#### THANK YOU!

We would like to officially thank the 11 organisations who financially supported Fertility Week: How Kiwis Make Babies.

Fertility Week is also made possible through the dedicated efforts of around 50 volunteers around the country – their time, energy and expertise made the campaign fly.

Last, but not least, thank you to everyone within our community who shared their stories with us, visited our websites, followed our Facebook posts and participated in our events and webinars. Fertility NZ exists to support you – thanks for letting us know that we're on the right track!

Fertility Week will return in 2018. Ka kite an au i a koutou!

## Have you seen our fertility information videos?

Did you know that we have a series of over 20 information videos? Each video features advice from experts combined with people sharing their own experiences. Each video is a few minutes long there is a wide range of topics. Check them out today!

http://www.fertilitynz.org.nz/information/information-videos/







# Chelsea's determination to lower her BMI for funded IVF treatment

Her weight-loss struggle is an additional hurdle, but Chelsea is staying positive.

Jared and I have been together nearly eight years and started trying to conceive more than six years ago. Along the way, I was diagnosed with Polycystic Ovary Syndrome (PCOS) and then, eventually, endometriosis after a laparoscopy 18 months ago. Jared has a daughter from a previous relationship and has been tested throughout our journey and all is OK on his side.

After a couple of years of trying to conceive I became quite worried about no outcome to date, so my GP referred us to a fertility clinic for the next step. Throughout our time as patients we tried monitored and unmonitored rounds of clomiphene and letrozole. Ovulation hasn't seemed to be an issue, however, still no luck. So after a recent review with our doctor, we have come to the conclusion that IVF is the next step.

We are currently working towards getting on the fertility treatment public funding wait-list as I'm outside the strict BMI range. It has been a constant struggle for me personally to lose weight. My doctor sat me down four years ago to tell me that I need to lose weight and I have been up and down since then. I am currently working with a nutritionist to break old habits and help with mindset.

This journey can be very lonely and lots of people don't understand how it can affect you as an individual. I was starting to feel quite isolated so I am very lucky to belong to a



support group through Fertility NZ – a lovely bunch of ladies who are going through the same issues. I am also very lucky to have a supportive partner who is with me all the way and always understanding when it comes to my weight loss struggle.

I have my off days but I'm still very positive about our journey going forward and determined more now than ever to get on that waitlist.

Thank you, Chelsea, for sharing your story for Fertility Week 2017





# TUI study assesses IUI treatment

Study findings show IUI treatment ought to be considered a first-line treatment. By Dr Emily Liu, Gynaecologist & Fertility Specialist, Fertility PLUS

Couples with unexplained infertility are often offered intrauterine insemination (IUI) as an alternative to in vitro fertilization (IVF). Yet the evidence for IUI as an effective treatment is lacking from earlier clinical trials. Guidelines in the UK recommended that IUI should not be routinely offered for couples with unexplained infertility. However, it is difficult for some of these couples to access public funding for IVF in New Zealand. Currently couples with unexplained infertility need to be trying to conceive for five years to meet the criteria.

The IntraUterine Insemination study

(TUI study) was therefore designed to assess the effectiveness of IUI in couples with unexplained infertility and an unfavourable prognosis of natural pregnancy. The trial was carried out by two clinics in Auckland, Fertility PLUS and Repromed, in conjunction with University of Auckland. A group of 201 women were enrolled and randomly assigned to either three cycles of IUI using Clomiphene as ovarian stimulation or three cycles of expectant management.

The TUI study found that women who had IUI treatment had a three-fold improvement in live births

compared to women who tried to conceive naturally. There were 31 live births from the IUI group and nine live births from the expectant group. There was no difference in the pregnancy related complications, such as miscarriage or ectopic pregnancy. The study concluded that IUI with Clomiphene is a safe and effective treatment for couples with unexplained infertility, and should be considered as a first-line treatment.

#### What is IUI?

IUI is a simple and non-invasive treatment. The woman receives mild ovarian stimulation to increase the number of eggs. The cycle is monitored with blood test and scan. The partner's sperm is placed into the uterus around the time of ovulation. The sperm then travel to the fallopian tubes to meet and fertilise the eggs. IUI is suitable for couples with open fallopian tubes, normal semen analysis and normal ovulation with or without ovulation induction.

Sharing her story is what helped Sarah get through the particularly hard days of struggling with infertility.

I'm Sarah Miller, I am 34 years old and I live in Auckland. I have an incredibly loving, supportive and wonderful husband of 5 years and I love my job as a marketing manager in the beauty industry. My life has not been without many difficulties from a young age and from these challenges I have faced, I have grown into a very independent, strong, courageous and very compassionate woman. However, nothing has challenged me more than this new battle I face in life... Infertility.

Kayn and I got married in 2013 and that same year we purchased our own home, travelled, worked hard and then we decided, IT'S TIME! We were so excited to create our own little family.

I was really disappointed when I got my first negative pregnancy test that first month. I think I may have even cried. I swear I had all the symptoms. Next month, negative... and this continued.

Nine months passes and I've read every blog, every "how to get pregnant" Google search answer and spent hours upside down. I'm frustrated. What am I doing wrong?! I started to feel quite lonely and I didn't want to tell anyone. I'm not sure why – I think I knew it was early and I knew I should be grateful for what I DO have in life.

Life was on hold every 'two week wait'. I would shake with nerves and excitement taking the pregnancy test each month but always to be bitterly disappointed. I read something the other day that said, "struggling with infertility is like dealing with the five stages of grief every month. You deny, bargain, get angry, cry and accept. Then you pick yourself back up and do it all over again." Bang on. I always allowed myself two hours to cry, be angry and sad then it was time to shake it off and be positive about the next month.

# Sarah and Kayn's story

I had been for scans, blood tests, to the naturopath, acupuncture, tried every relaxation technique I could, cut down my exercise, changed my entire diet, and started fertility meditation. If it was suggested, I would try it!

I was now desperate to get pregnant as my dad had been diagnosed with cancer earlier in the year and the heart-breaking reality was that he wouldn't be around for as long as we had hoped. I wanted so badly to give him a grandchild or at least be able to tell him I was having my own child to give him an extra reason to keep fighting hard. Sadly, I held Dad's hand as he took his last breath in February 2015.

"Coming home from a trip to Europe not pregnant was a huge tell-tale sign. If Paris couldn't get me naturally pregnant, nothing could!"

A soul-hugging trip to Europe followed that April and then coming home not pregnant was a huge telltale sign. If Paris couldn't get me naturally pregnant, nothing could!

I went to see my wonderful doctor again and she referred my husband for a semen analysis and, well...problem solved! So there we sit in the severe Male Factor Infertility bracket. There are no words to express this feeling of being told your chance of having children is pretty much non-existent. However, my husband and I aren't really the 'sit around and cry about it' kind of people so we dusted ourselves off pretty swiftly and quickly felt grateful that IVF is there as an option for us. HOPE.

My doctor referred me to a fertility clinic and we had our first appointment four weeks later. We met with our specialist who quickly sent us off for tests upon tests which took seven weeks to process. We quickly realised, this was going to be a huge test of patience. My husband would've told you back then – I have NONE.

Our first appointment proved that we needed to go straight to IVF (Invitro Fertilisation) with ICSI.

We are lucky that my hormone levels are all good. Nothing to celebrate about, but in the low-normal bracket. So are Kayn's – so we're dealing with "unexplained" MFI.

Basically, in short, this is how our four cycles of IVF followed:

- June 2015: We went into our first (private) cycle with such excitement and hope. It all went well; we had 12 eggs collected but only one made it to a blastocyst stage which we froze due to my high progesterone levels. We did a FET a few months later but it ended in a chemical pregnancy. Reality hit us hard! This wasn't going to be easy.
- January 2016: Cycle #2 (private) was a nightmare from the start. They put me on a long protocol over summer but I ovulated right before egg collection and lost up to 16 eggs. Three were collected, but they were so immature that none fertilised. This was particularly devastating as it had been such a hard round, not just mentally but physically. My body was wrecked; I was left bruised, bloated, in pain and broken-hearted.
- May 2016: Cycle #3 (funded) was back on the short protocol which went well with 10 eggs collected. This cycle was looking good, we were so happy! However, we then got the call on Day 1 that NONE had fertilised. All over. Again.



• November 2016: Cycle #4 (funded cycle) was again on the short protocol and this round was looking positive. Kayn has the TESA done this round in hopes of finding some better sperm (although the fresh sample showed huge improvement after six months on his 'fertility diet'). We had seven eggs collected and three fertilised! One made it to freeze and the other viable embryo we had transferred on Day 3. SURELY this will be our time! SURELY this will be our baby! Two weeks later, a BETA test of 0.5 comes

back. Another failed round.

Each failed round is particularly hard to handle but having this to deal with, especially right before Christmas,is heart-wrenching. We should be celebrating and having the best Christmas ever. Instead we just want the day to be over!

Although infertility is hard for anyone to truly understand, we have been quite open about our journey with our friends and family if we were asked about it. We never moan or go on about it to others but for us, it's

all-consuming. I'm extremely grateful for my life and to still be classed as young to go through this, however, it really takes its toll, it's terrifying, it is a very lonely

road and it's exhausting to have to constantly deal with this heartbreak. My husband and I are closer than ever as we have always committed to being by each other's side the whole way and vowing to always listen and be there for one another. We are stronger than ever for having to face this.

One thing I hate is that I feel like this is starting to define me. I have been through this for over three years now and month after month and IVF round after round; this is my life and a struggle that I face every day. You can't hide from babies/kids, pregnant women, families, etc, and they are all a reminder of what we want more than anything in this world but cannot have.

I'd love to share my story as these are what helped me get through the particularly hard days. However, I struggled to find stories from the younger professional couples like us who have had numerous failed cycles of IVF. Yet when I sit in my clinic, the waiting room seems to be filled with couples our age.

We were then left holding the last ounce of hope for our last and only frozen embryo. We kept delaying this out of fear and what it would do to us if it didn't work but in May 2017 we did it. We transferred our lucky last frozen embryo. The 'not so good' one.

Two weeks later we received the most shocking and best news of our lives... it had worked! We were pregnant! It was hard to believe that it was actually happening and the first three months were full of anxiety and doubt but I'm now over five months pregnant with a healthy baby and I now truly believe that a dream is never too big to achieve.

Thank you, Sarah, for sharing your story for Fertility Week 2017



### noticeboard

Support Group

#### **AUCKLAND: PREGNANT** AFTER FERTILITY TREATMENT

Sunday 4th February sunday 4th March Sunday 1st April

#### **AUCKLAND: CASUAL COFFEE**

Tuesday 20th February Tuesday 21st March Tuesday 17th April

#### **AUCKLAND: FERTILITY** SUPPORT SERIES

Tuesdays 6th, 13th, 20th March

#### **AUCKLAND: SINGLE WOMEN**

Sunday 28th January sunday 25th February sunday 25th March sunday 29th April

#### **AUCKLAND: SECONDARY** INFERTILITY

Sunday 28th January Sunday 25th February sunday 25th March

#### INVERCARGILL

Tuesday 9th January Wednesday 7th February Tuesday 6th March Monday 9th April

#### **HAMILTON**

Saturday 20th January Saturday 17th February Saturday 17th March Saturday 21st April

#### DUNEDIN

Tuesday 6th March Tuesday 3rd April

#### HAWKE'S BAY

Sunday 18th February sunday 15th April

#### WELLINGTON

Tuesday 20th February Tuesday 3rd April

#### **CHRISTCHURCH**

Tuesday 23rd January Tuesday 27th February Tuesday 27th March Tuesday 24th April

#### Invercargill support group

Amy, facilitate regular support gatherings in Invercargill. The free-of-charge sessions are held monthly and open to anyone experiencing infertility. The sessions are very casual with a 'coffee and chat' format (some sessions will have guest speakers). Please contact Aimee or Amy on invercargillsupport@fertilitynz.org.nz to enquire or register your interest.



### Local information How can we help you in your area?

#### Fertility NZ **Local Contacts**

#### Whangarei

whangareisupport@fertilitynz.org.nz

aucklandsupport@fertilitynz.org.nz (Fertility Support Series, Casual Coffee, Pregnant After Fertility

secondarysupport@fertilitynz.org.nz (Secondary Infertility)

singlewomensupport@fertilitynz.org.nz

#### Hamilton

hamiltonsupport@fertilitynz.org.nz

#### Tauranga

taurangasupport@fertilitynz.org.nz

#### Rotorua

rotoruasupport@fertilitynz.org.nz

#### Gisborne

gisbornesupport@fertilitynz.org.nz

#### Hawke's Bay

hawkesbaysupport@fertilitynz.org.nz

#### Wellington

wellingtonsupport@fertilitynz.org.nz

nelsonsupport@fertilitynz.org.nz

#### **West Coast**

we st coast support@fertilitynz.org.nz

#### Christchurch christchurchsupport@fertilitynz.org.nz

**Central Otago** 

#### central otago support@fertilitynz.org.nz

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