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THE Dandelion

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

MARCH 2016

Join us for Fertility Week

We invite you to be part of Fertility Week 2016, the week of 9-15 May.

Fertility Week is a time when New Zealanders think about fertility – their current fertility, their future plans for a family, or friends and family affected by infertility. We'd love you to become involved in Fertility Week 2016, in whatever way suits you! Again this year, Fertility Week has something for everyone. Here is an outline of what will be happening during Fertility Week:

- Reliable, practical information and guidance, plus stories from our members on www.fertilityweek.org.nz
- Webinars: Presentations by fertility experts followed by Q&A sessions. Visit www.fertilityweek.org.nz at 8pm

each weeknight during Fertility Week!

- Regional events: An array of events will be happening around the country during Fertility Week, such as quiz nights, coffee evenings and guest speakers. If you are registered as a Member of Fertility NZ (and you've ticked 'yes' to regional support), you'll hear about your closest event via email. Otherwise, register your interest by emailing support@fertilitynz.org.nz (with your city/region), or keep an eye on www.fertilityweek.org.nz or our Facebook page closer to the time.

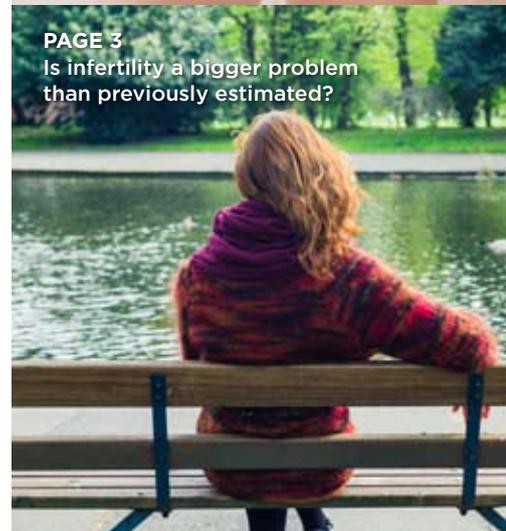
So join us, and find out what you need to know, now!

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Fertility Week
9-15 May 2016

what you need to know, now

www.fertilityweek.org.nz





Welcome Notes

Welcome to *The Dandelion* newsletter.

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.

Some of you may have attended the Redefining Family Conference which was held in Auckland during January. Fertility NZ was pleased to be part of the organising committee for this conference, which focussed on family building via adoption, donor conception and surrogacy. The programme was excellent, and as well as the array of academic and professional topics, we were delighted to hear so many people openly sharing their own stories and experiences.

Fertility Week is just around the corner! It will be held from 9-15 May, during which time there will be information, stories, free webinars and events around the country. 'Fertility Week: What you need to know, now' will have something for everyone, no matter what stage you are at! Register your initial interest by support@fertility.org.nz, or keep an eye on www.fertilityweek.org.nz. See you there!

Thanks to a wonderful network of volunteers, we have a great coverage of support groups throughout the country. Nelson is our newest support hub, and the facilitators would love to meet you there. See the back page for a group or event nearest you. Our support groups are a safe space to

gain support and connect with others 'in the same boat'. New people are always welcome.

Fertility NZ held its AGM in November. We are pleased to report that our Executive Committee is again at capacity. You will see below the full list of Committee Members.

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.

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.

Fertility NZ's Executive Committee

Nigel McKerras – President,
Treasurer

DeAnne Brabant – Secretary

Medical Advisors

Dr Janene Brown
John Peek, PhD
Dr Guy Gudex

Other Corporate Members

Nina Williams

Regional Representatives

Rebecca Hellberg-Walker (Christchurch)
Nicky MacKenzie (Wellington)

General/Consumer Members

Cate Curtis, PhD
Loula George
Anita Killeen
Cathy O'Sullivan
Hayley McManus

Christchurch Information Events

Genea Oxford

'Feeling your way through Infertility' discussion series by Dr Lois Tonkin. These group discussions will explore the emotional impact of creating a family through assisted reproduction.

- *When Things Don't go as Planned: Living Hopefully with Infertility*

WHEN: Thursday 7 April, 6.15pm–7.30pm

- *Is Blood really Thicker than Water? Using Donor Sperm or Eggs to build your family* (with Professor Ken Daniels)

WHEN: Thursday 25 August, 6.15pm–7.30pm

- *Fertility on Ice: The possibilities and limitations of freezing your eggs*

WHEN: Thursday 27 October, 6.15pm–7.30pm

WHERE: Genea Oxford
First Floor, Forte Health building
132 Peterborough Street
Christchurch Central

REGISTER: go to www.geneaoxford.co.nz and register on the 'free seminars' page.

Fertility Associates

- *Fertility Information Event*

Worried about your fertility? Fertility Associates is holding a free fertility information event for anyone experiencing difficulty getting pregnant or wanting to know more about fertility. Find out about fertility issues, lifestyle factors, basic tests, treatment options, support, funding and more.

WHEN: Wednesday 23 March, 6.00pm–8.00pm

WHERE: Fertility Associates
Leinster Chambers, 249 Papanui Road
Christchurch

REGISTER: email dkimber@fertilityassociates.co.nz or phone 03 375 4000.

Infertility common amongst Otago-Southland women



A paper appearing in the *New Zealand Medical Journal* reports the results of a 2011 survey of more than 1000 Otago and Southland women about their fertility experiences, expectations and knowledge.

The results show that amongst those who had ever tried to become or been pregnant, a quarter (25.3%) had experienced infertility, meaning they had tried for at least 12 months or needed medical help to conceive.

Otago PhD student Antoinette Righarts, who co-ordinated and analysed the survey, says nearly three quarters of women who experienced infertility sought medical help, and almost a third of infertile women had received some form of specialist treatment. "While

most women resolved their first experience of infertility with a live birth, a quarter had not. Unresolved infertility was more likely for women who first experienced the problem when aged 35 or older and for those more socially deprived," Ms Righarts says.

Professor Wayne Gillett, a fertility specialist and paper co-author, says these data support findings from the long-running Dunedin Multidisciplinary Study released earlier this year, confirming that infertility is a bigger problem than previously estimated. "Such high proportions of women experiencing infertility and seeking help to resolve their fertility issues will continue to put substantial pressure on under-funded infertility services," Professor Gillett says.

Our story

of Unexplained Infertility

Siân and Steve's story was kindly shared for Fertility Week 2015.

Hi, I'm Siân (aged 38) married to Steve (39), and proud parents to Aleksandr (known as Sacha to his mates) and another little one due in a couple of weeks.

This is the story of our (in)fertility journey, which is described, as "unexplained fertility". It's annoying to have to describe it as that as so many times through our journey I just wish we could have got 'the answer' as to why things never happened naturally for us. Even after (just about!) two babies later I still don't think I've quite got to grips with that, but that's the hand we were dealt nonetheless.

I've wanted kids for as long as I can ever remember. Steve and I met in 2000 and I knew from the first time we met we would either be best friends or a couple. I got lucky and got both of those things! We got married in 2005 when I was 28 and he was 29.

While kids were definitely on the agenda, we didn't have a particular timing in mind – we were living overseas at the time and having fun experiencing life footloose and fancy free.

'Inconvenient' timing

In 2006 we moved back to New Zealand and put down some firmer roots, buying our place and settling into interesting jobs. We started to talk a little bit about starting a family but decided to put it off a little – we had friends' weddings coming up overseas and thought it would be 'inconvenient' timing to be pregnant and doing more travel.

Oh how I laugh about that now – at the assumption that we were in

control of things! It's been a useful life lesson that I've taken on board since: take your opportunities as they come up; life goes on.

On my 31st birthday I woke up with a clear determination that I didn't want to wait anymore – I was excited to be starting on the journey of creating our family and wanted to start now. Steve didn't need any convincing so we got into it.

Skip to a year later and we were beginning to wonder why things weren't happening for us. We knew that it could take time and had read that if it hadn't happened after 12 months of trying it would be worthwhile to get things checked out with your GP. So off we went. I got blood tests done to determine whether I was ovulating and Steve got his swimmers checked out.

Excitement and trepidation

My bloods came back positively but Steve's swimmers looked a little lazy. Our GP referred us to Fertility Associates and we went to our first appointment with both a sense of excitement and intrepidation – these were the people who could solve all our problems and help us make a baby!

Our doctor was the fabulous Dr John Hutton (now retired). We formed a great rapport with him and he seemed to speak the same kind of language as us. He explained that fertility issues generally fall into two camps (or both): structural (e.g. blocked tubes) or functional (e.g. hormones not working properly).

We started on the journey of figuring out where our issues lie, starting with the least invasive stuff first and

crossing that off, before moving into more heavy duty territory. Cue 3 years of tests, different fertility treatments and, finally, 3 rounds of IVF.

More and more... and more

To give a little snapshot, we experienced ...

- More blood tests and sperm samples than I ever imagined. Happily Steve's swimmers were given the all clear in the end, though I seemed to have a short luteal phase (the lining of my uterus may have a tendency to shed before a fertilised egg has a proper go at embedding).

- More poking and prodding in my nether regions than I ever imagined. I underwent two failed attempts at trying to have the dye test done to see whether my tubes had a blockage.

This involved about an hour, each time, of a doctor trying to put a tube up into my cervix and into my uterus to inject dye, and trying to stay relaxed through the procedure!

We had to give up as my cervix just seemed to be too bendy. I thought my body was broken and there was something seriously wrong with me, cue many tears and lots of hugs from Steve. I also had my internal 'environment' tested to see whether it was hostile to the survival of Steve's swimmers (it was only marginally).

- More people knowing and directing our sex life than I ever imagined. One set of treatments involved timed intercourse, with Steve having to deliver his swimmers at a particular time (10pm was the magic ▶



“So many times through our journey I just wish we could have got ‘the answer’ as to why things never happened naturally for us.”



“All through my pregnancy I shielded myself from truly believing – until the last month or two when I allowed myself to dare to think we might be having a baby.”

hour) with an internal examination the next day to see how my body was reacting.

Outside of this particular treatment we had to have sex every other day during my times of ovulation. Early on I also had a spell on the drug Clomiphene. The worst side effect of all of these things was the inevitable drain on the fun and spontaneity that usually goes along with trying for a baby.

After many inconclusive tests and treatments over the years we finally ended up in ‘invasive’ territory and I found myself needing to have a laparoscopy and hysteroscopy procedure (key hole surgery to check out my tubes from the outside and well as going up through the cervix to check out my uterus from the inside).

It was my first time under general anaesthetic, which I found scary. My tubes checked out ok (finally got that dye through!) but my doctor found stage 2 endometriosis and two fibroids. This was removed – my doctor described it as ‘pulling the weeds from the garden’ – but, puzzlingly all this in itself was not really enough to prevent us from getting pregnant.

Bringing out the big guns

With that all done and the years ticking by it was time to reach for the big guns – IVF. We qualified for public funding and went on the waiting list, with our first round scheduled for 2011. It wasn’t to work out for us on this round: we ‘only’ got 4 eggs (on the low side for IVF) and none of them fertilised. Steve and

I thought that this could be the answer – Steve’s swimmers can’t crack my eggs – but no, our doctor confirmed that this was just an anomaly. Given such an all-in-all failure, our doctor didn’t count this as an IVF round, so we were back being scheduled again for round two.

This time we found one of those pesky fibroids had grown back and should ideally be removed before proceeding. Our lovely doctor got me a hospital appointment within a few short months and I went under again for my second operation. ‘Weeds pulled’ we started on our second round of IVF, tweaking my drug dosage a bit.

This worked wonders and we collected a whopping 19 eggs. Eleven were fertilised using ICSI (where Steve’s swimmers were inserted into each egg instead of leaving it to mother nature) and three matured to day 5 blastocysts (embryos). This was a great result and I had a ‘fresh’ embryo transfer.

Heartbreak

Waiting to hear whether I was pregnant was agony ... I was! I could not believe it! It had actually worked! Unfortunately, bad news was to come.

Blood tests showed that the embryo wasn’t developing and would never

become a viable baby. I would miscarry. Steve and I had planned an overseas break and after talking to my doctor we decided that we would leave it to happen naturally, rather than bring it on with drugs.

Halfway through our 5 week break I miscarried. Even knowing that it was going to happen didn’t stop the physical and emotional pain. Our potential baby had gone.

We tried to look at the bright side – we still had two frozen embryos. Over the year these were separately transferred but they weren’t to be our babies either.

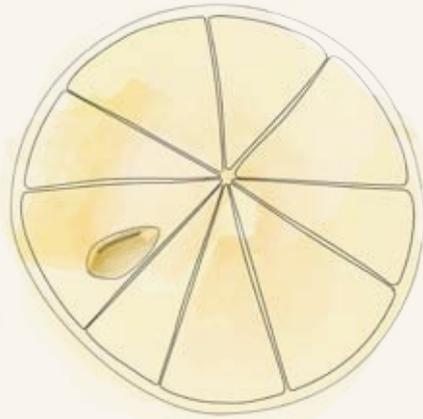
Another round

We found ourselves looking at another IVF round – our last publicly funded one. At round number three we collected less eggs (but still a whopping 11), with 2 maturing to day 5 blastocysts (embryos). I didn’t want to get my hopes up too much (so many emotional ups and downs over the years) but I got a positive pregnancy result. I didn’t want to believe it and I have to admit that all through my 9 month pregnancy I shielded myself from truly believing I was going to have a baby until the last month or two which is when I allowed myself to dare to think we might be having a baby.

Despite my disbelief I am a proud Mama to nearly two-year old Sacha. We have his ‘first baby photo’ – a picture of him as a 5-day blastocyst – proudly displayed in his room.

And now I have another to add to it. His sister or brother, frozen at the time he was transferred into me, is waiting to be born in a couple of weeks. After 7 years of wishing, hoping, crying, punching pillows and shouting “why me?!” it is more than I ever thought possible.

We still don’t know exactly why we couldn’t conceive naturally. While tests and procedures did reveal things we didn’t know we had, in themselves they aren’t enough to stop conception. That’s the way it is for us. If it’s like that for you too, then my heart is out to you. It’s a hard road. Stay strong.



RESEARCH: The PIP studies

The Pipelle for Pregnancy (PIP) studies are research trials currently recruiting in Auckland, Wellington and Christchurch. The purpose of the studies is to investigate whether performing an endometrial pipelle procedure can help women to get pregnant.

The PIP studies

The PIP studies are three separate trials of endometrial pipelle sampling in different groups of participants:

- PIP-IVF (in women undergoing IVF/ ICSI/embryo transfer)
- PIP-UE (in couples with unexplained infertility)
- PIP-PCOS (in couples with subfertility related to polycystic ovarian syndrome)

All three PIP studies are randomised controlled trials. This means that women who take part in the study are randomly allocated to either undergo the pipelle procedure, or not.

Different eligibility criteria apply to each study. If you are interested in taking part in one of the PIP studies, please contact the PIP study coordinator who can assess your eligibility.

Why are we running the PIP studies?

Researchers have found that performing an endometrial pipelle sample in women who had unsuccessful IVF cycles increased their chance of pregnancy in the next IVF cycle.

However, it is not known whether sampling is also helpful for women on their first or second IVF cycle, or who are having a frozen-thawed embryo transfer. It is also not known whether endometrial pipelle sampling could be beneficial in couples with unexplained infertility, or subfertility related to PCOS, who are trying to conceive with sexual intercourse.

Endometrial pipelle sampling may increase the chance of pregnancy in these women too.

The three PIP studies aim to assess whether pipelle sampling improves pregnancy and live birth rates in the three different groups of participants above.

How does endometrial pipelle sampling increase pregnancy rates?

It is believed that endometrial sampling may increase the chance of pregnancy because it disturbs the lining of the womb and causes a small wound-healing response. Biological factors which are then released due to this response are thought to be helpful for implantation of an embryo into the lining of the womb. As implantation of an embryo is the first step in establishing a pregnancy, endometrial pipelle sampling might lead to a higher chance of pregnancy.

Researchers found that performing an endometrial pipelle sample in women who had unsuccessful IVF cycles increased their chance of pregnancy in the next IVF cycle.

The pipelle procedure

Endometrial pipelle sampling (also known as endometrial biopsy, injury or scratching) is a common procedure often used to collect endometrial samples from women.

The pipelle procedure is similar to having a smear test done. A speculum is inserted into the vagina. Then a thin plastic sampler (the pipelle) is inserted gently through the cervix and into the

womb. The pipelle procedure takes 1–2 minutes and involves gently moving the pipelle back and forth to obtain a small sample from the lining of the womb.

Some temporary discomfort or cramping may be experienced during the procedure.

Participating in the PIP studies

Taking part in the PIP study offers women and couples a 50% chance of undergoing a new procedure (endometrial pipelle sampling) that may help them to get pregnant.

Participants in the PIP study are also providing researchers with important information about endometrial pipelle sampling, including whether this procedure is beneficial for different subfertile groups of women and couples. By being involved in the trial,

participants will also contribute to helping subfertile women and couples in the future to receive the best possible chance of having a baby.

Taking part in the PIP studies is completely voluntary, and participants who take part are free to withdraw from the study at

any time. There is no cost to take part in the PIP studies.

If you have any questions about the PIP studies, would like some more information, or are interested in taking part, please get in touch with the PIP study coordinator:

Sarah Lensen
pip@auckland.ac.nz
 09 923 9487
www.fmhs.auckland.ac.nz/pip

noticeboard

Support
Group
Dates

AUCKLAND, CONTACT GROUP

Tuesdays 15th, 22nd
and 29th March

AUCKLAND, SECONDARY INFERTILITY SUPPORT GROUP

Saturday 19th March
Saturday 23rd April
Saturday 28th May

AUCKLAND, CASUAL COFFEE GROUP

Tuesday 15th March
Tuesday 19th April
Tuesday 17th May
Tuesday 21st June

TARANAKI SUPPORT GROUP

Wednesday 9th March
Wednesday 13th April
Wednesday 11th May
Wednesday 8th June

NELSON SUPPORT GROUP

Tuesday 8th March
Tuesday 12 April
Tuesday 10th May

WELLINGTON SUPPORT & CONNECT

Wednesday 6th April
Wednesday 11th May
Wednesday 1st June

CHRISTCHURCH SUPPORT GROUP

Tuesday 22nd March
Tuesday 26th April
Tuesday 24th May
Tuesday 28th Jun

DUNEDIN SUPPORT GROUP

Tuesday 1st March
Tuesday 5th April
Tuesday 3rd May

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

aranakisupport@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

dunedinsupport@fertilitynz.org.nz

Donor Conception

donorconception@fertilitynz.org.nz

Nelson Support Group

There is a Nelson support group made up of people who all understand first-hand the heartache of infertility and the ups and downs of fertility treatment. We meet in the evening on the second Tuesday of every month at a location in Central Richmond. 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 Shannan or Susannah, email nelsonsupport@fertilitynz.org.nz

This material is supported by way of an educational grant from Bayer New Zealand Limited. The information submitted is intended to assist health care professionals and patients in forming their own conclusions and making decisions, but may not represent a comprehensive listing of all available information on the subject. The views and opinions expressed by the individual presenters do not necessarily represent the opinion of Bayer New Zealand Limited.

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CONTACT US

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• post: Fertility New Zealand, PO Box 28262, Remuera, Auckland 1541 • Visit us on Facebook!