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THE Dandelion

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

MARCH 2018



TRY A LITTLE KINDNESS

The most effective treatment when facing fertility issues? Kindness, says Sarah Friis.

The fertility journey can be tough going, even for the most resilient. Many of us, particularly Type A personalities, are accustomed to achieving our goals through hard work and a simple determination to succeed. Should we deviate from the path of success, we have a well-tuned self-critic to set us smartly back on the straight and narrow. Unfortunately, these skills, while highly effective in our professional careers, are hopelessly ineffective when dealing

with fertility issues. And it is this sense of hopelessness and powerlessness that we struggle with the most. But what if there was another, more effective way of coping? One that could not only support us on our fertility journey, but also have a positive effect on every other aspect of our lives?

Our most common technique for motivating ourselves to succeed is to listen to our self-critic. We listen

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Welcome Notes

Welcome to *The Dandelion* newsletter.

The challenges faced by people experiencing infertility are many and varied. Far from being purely a health issue which requires medical resolution, infertility can affect all aspects of our lives. Seemingly everyday events such as hearing the news of someone's pregnancy; or a well-meaning relative asking about the pitter-patter of tiny feet; or being confronted by Mother's / Father's Day promotions, can be profoundly stressful.

Research shows that in-person support has significant positive impact, both physiological and emotional. If you haven't yet attended one of our support groups, please consider it. All our groups are supportive, confidential spaces for sharing experiences and providing understanding, friendship and hope. There are often themes or guest speakers and you can share as much, or as little, as you feel comfortable with. Most support groups also have a closed Facebook page for people to connect between meetings.

Our volunteer facilitators

typically come to Fertility NZ in one of two ways – either they found our support groups invaluable during their journey, or they wish that there had been support for them and want to provide it to others. Thank you to our newest facilitators, Amy and Aimee from Invercargill, who fall into the latter category, for sharing your stories with *The Dandelion* (page 4).

Did you know that there is world-leading research into PCOS currently being conducted at the University of Otago? Dr Rebecca Campbell shares an insight into her team's fascinating work on page 6.

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

Seeking Auckland-based volunteers

Our wonderful Auckland Committee currently has some vacancies and would welcome new members to help support our community.

We are seeking someone to help with, specifically: coordinating registrations, promotion and logistics for our support groups. Time commitment varies with group timing – between one and 10 hours per month. This could be on a job-share basis. There are also spaces available for group facilitators – this would suit women and men who have completed their fertility journeys (either with or without children) and are in a strong position to provide support. Facilitators should be available on Tuesday evenings, to run one three-week group per year (three sessions). Facilitators are also required to attend a facilitators' professional training day (free of charge) annually and possibly observe a group initially. These roles are completely voluntary. If you are interested or would like to learn more about how you could join our fantastic network of Auckland volunteers, contact Karina on aucklandsupport@fertilitynz.org.nz

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.

Try a little kindness

◀ From page 1

because we are hard-wired for a negativity bias: it's more familiar and, strangely, it feels safer to beat ourselves up as a way of coping when things are not working. The opposite and less common response to a negative outcome is kindness and compassion. This is often mistaken by the self-critic as weak and ineffectual – but research has proven that this is not true.

So, how do you use kindness as a way of coping? Firstly, take note of how you are currently coping. What do you say to yourself when things go wrong? What is the tone of your voice? Do you sound like a compassionate friend? If not, ask yourself: how might your compassionate friend respond to you in such circumstances?

When you do notice your self-critic, don't shut it down – this is self-defeating. Instead, turn towards it with kindness and appreciate that it is only doing what it knows best. Its intention, through years of evolutionary programming, is

to protect us from hurt. From this perspective we can also appreciate that this approach may not be the kindest and offer, as a dear friend would, an alternative suggestion.

While the above works well when dealing with acute distress, sometimes it's the long periods of waiting which require a different type of coping through kindness. In these times, the kindest thing we can do for ourselves can also be the simplest. And that is to ask yourself: what do I need most right now? The answer may come in the form of a massage or a cup of tea with an understanding friend – or, even more simply, to take three deep breaths. Try imagining that you have a 'bank of resilience'. By asking yourself what you need and responding with

a comforting action you are making frequent deposits of kindness into this 'bank' – all of which strengthen your metaphorical coping muscle in the same way that consistent exercise strengthens your body's muscles.

What might surprise you most is the simplicity of these recommendations. However, when used with consistency, they are proven methods for coping with the inevitable highs and lows of any fertility journey.

In order to cope with kindness, remember these three key points:

- Turn towards your critical comments with kindness and offer an alternative approach
- Respond to yourself as you would a dear friend
- Ask: what do I need right now?

Sarah Friis has a Master's in Psychology and is co-founder of The Performance Team, a leading New Zealand consultancy dedicated to unleashing the power of team. In her spare time she runs two-hour workshops on Compassionate Coping through Fertility at two of Auckland's fertility clinics.

PGS + NGS = better results with IVF?

A recent publication (Weissman, 2017) presented results of a survey across fertility clinics in 70 countries about Pre-Implantation Genetic Screening (PGS) practices. The survey, which gathered insight in 2015 from 386 clinics that provide 342,600 IVF cycles annually showed that 16% of clinics utilised Next Generation Sequencing (NGS), the latest technology in testing embryos. It concludes:

"...the technical landscape of PGS is currently undergoing a dramatic change. It is highly likely that most PGS cases are now being carried out by NGS rather than aCGH" (the previous technology for PGS).

Global research is indicating that PGS with NGS technology could be the new norm for IVF treatment. In October 2017, the American Society of Reproductive Medicine conference presented research in October that showed that IVF with PGS with NGS could improve the chance of pregnancy by up to 25% in women aged 35–40. It should be noted though that PGS, with any method, does not increase the overall chance of a baby from an IVF cycle, but can help with selecting the best embryo to transfer first, and to rule out embryos that have no chance of implanting. This can reduce the time to pregnancy and

can reduce the chance of miscarriage.

For those taking part in genetic screening, once the cells are taken, the embryos need freezing whilst awaiting the results on embryos. It is believed that that freezing embryos and transferring in a frozen thaw cycle provides a more favourable uterine environment for the embryo. New Zealand and Australian data shows that the live birth rate is actually higher for over 35 year olds with a frozen embryo transfer versus fresh embryo.

The latest research is indicating that PGS with NGS technology, and a frozen embryo transfer may give the highest chance of the birth of a healthy baby.

Repromed was the first NZ clinic to offer PGS with NGS technology, and in 2017 launched an Auckland based screening service with the University of Auckland's Genomic Centre.

Meet Amy and Aimee, supporting our community in Southland



Amy's story

Isolated, afraid, lonely, guilty – these are feelings I know well from first-hand experience. My name is Amy, I am 34 years old and I live in a small town just outside of Invercargill. I am really excited to have joined Fertility NZ as one of the Group Facilitators of the Invercargill Support Group. My desire to be a facilitator of such a group was very much born from my own struggles with fertility and the journey I have been on.

As a fit, happy, healthy 28-year-old I came off the contraceptive pill and thought within a few months my partner and I would be on our way to starting our family. Months went by, those months turned into a year, that year into two and the baby I longed for was nowhere on the horizon. I went to my GP who was proactive about the situation and sent me and my partner for some tests as well as referring me to a private gynaecologist. The tests came back normal for both of us, so I was referred for a laparoscopy. After the surgery I was told that I had a blocked tube and was referred to a fertility clinic. It felt like at least we were making progress.

At my first appointment with the fertility clinic the doctor looked at everything sent through to him and could not tell why I had been told I had

a blocked tube. To this day I still do not know whether I have said blocked tube! Somewhere between the surgery and this appointment I had also stopped having regular periods, something which I had never had trouble with before. We tried monitored rounds of clomiphene but unfortunately had no luck. We were told we would need IVF and put on the public waiting list. I remember after being told this I didn't really pay attention as the doctor explained the process as I couldn't believe this was happening to me, and never thought we would need to go that far to have a baby.

Unfortunately, we were caught up in a change of the fertility clinic being run by the District Health Board to a privatised organisation. This further extended the already tedious wait and five years had quickly rolled around. I had become a shell of my former self. I found getting out of bed difficult, I avoided seeing my friends, I threw my energy into working out at the gym in an almost obsessive unhealthy manner and I cried a lot! Recognising I was potentially suffering from depression I saw my GP who was again proactive and sent me for counselling. Taking the step and attending counselling was by far one of the wisest decisions I made in my fertility journey.

"I remember I didn't really pay attention as the doctor explained the IVF process as I couldn't believe this was happening to me!"

We had our first round of IVF in September 2016. I didn't know anyone who had been through the process and I wasn't on any online forums, so I was going in almost blind. When I wasn't responding to the drugs and was told my round might be cancelled my heart broke. I didn't know this was even a possibility! Thankfully with an increase in dose we made it to egg collection where they collected four eggs. Not a great number but our amazing doctor kept repeating, "it just takes one". And one egg was all that fertilised. I had a day two transfer which I did not know at the time was a bit unusual. That day two transfer is now my beautiful smiley 8-month-old son.

I always vowed when I got through to the other side of the journey I wanted to help others who were struggling with fertility. My partner was so supportive and positive, but he didn't understand. My friends didn't understand. My family were fantastic,

but they didn't understand either. How could they if they hadn't been through it. On this journey we need people who understand but I had no one to turn to.

I met Aimee in our antenatal class and I wish more than anything we had met many months earlier. There was no support group in our area at the time and I reached out to my fertility clinic but due to confidentiality they were unable to give me the details of anyone near me going through treatment. I wonder now how different things might have been had I just had that network of a support group.

Aimee and I had talked about restarting up the Invercargill Support Group late last year. After our conversation, Aimee was in contact with Fertility NZ almost immediately, she has this great quality of not messing around at getting things done. We have a lovely group of members who are so supportive, understanding and helpful with each other. It's great to be a part of and we want to reach out to as many people as we can. Our monthly catch ups are informal, safe and confidential. If you are in the Southland area, please do not struggle alone. Reach out to us – we would love to hear from you.

Aimee's story

I naively started our fertility journey thinking it would be easy for us. I was 26 with no prior fertility issues that I knew of, but my partner had a vasectomy 10 years prior, the right decision for him at the time.

Very early in our relationship, we decided to try a vasectomy reversal first (ignoring the terrible rates of success for a vasectomy over 10 years prior). Unfortunately, this was unsuccessful with a sperm count of two (not million, just two...) then zero. We turned to then Otago Fertility Services to find out our options.

Unexpectedly after 6 months the sperm count rose to 0.1million per ml and a TESA was avoided, much to my partner's relief! The count wasn't enough for natural conception, so we went ahead with starting the IVF process.

To add in a complicating factor, I was diagnosed with polycystic ovaries during a routine scan.

My first round was abandoned due to no eggs growing over 9mm, the drugs were changed for a second round and the same thing happened again. Thankfully on the third round, everything happened as planned and three embryos made it to day 3, but unfortunately the fresh transfer didn't take. During this time we had to wait for the changeover in Dunedin to Fertility Associates which caused a long delay for our frozen transfer.

In hindsight, this was a blessing because it gave me time to get myself sorted emotionally. It took me to breaking point to finally reach out to a fertility counsellor and it was the best decision that I made. The counsellor helped me to realise that I was constantly making myself busy trying to avoid thinking about our treatment and to make the time pass faster. I needed to de-stress my life so I started going to yoga, daily mindfulness, quitting sugar and caffeine. Going in to my frozen transfer I wasn't the stressed, highly-strung person that I was previously and I believe 100% that this impacted on the success of our transfer who is now our gorgeous 8-month-old girl.

After going through the treatment and opening up about our journey, I have found myself in a place to offer support for those going through similar emotions. I remember sitting in the waiting room with other people holding drug bags and wanting to reach out and share support, advice and stories, but no one made eye contact or said a word. The more I talked about my treatment, the more people I found who had similar experiences. This included Amy, who now co-facilitates the Invercargill support group with me.

I found that while my friends were compassionate, I spent so much time explaining the process to them and they didn't have true understanding of the emotional turmoil that is fertility treatment.

I write this piece the morning after our fourth support group meeting. A



"It took me to breaking point to finally reach out to a fertility counsellor and it was the best decision that I made."

common theme has been "I thought the group was going to be women sitting around crying" and while crying definitely does happen as people go through the highs and lows of treatment, there is also many laughs, stories and advice shared, and chocolate biscuits eaten. Within the group is a wide range of experiences with people at many stages of treatment.

This year we would like to add to our family but as the third embryo didn't survive the thaw, we will be starting from the beginning. The support group that we reinvigorated to help others will undoubtedly be where I turn to for support in the future.

Contact Aimee and Amy to join the Southland group for their monthly meetings supported by a closed Facebook group – invercargillsupport@fertilitynz.org.nz

Polycystic ovarian syndrome

Is it all in our heads?

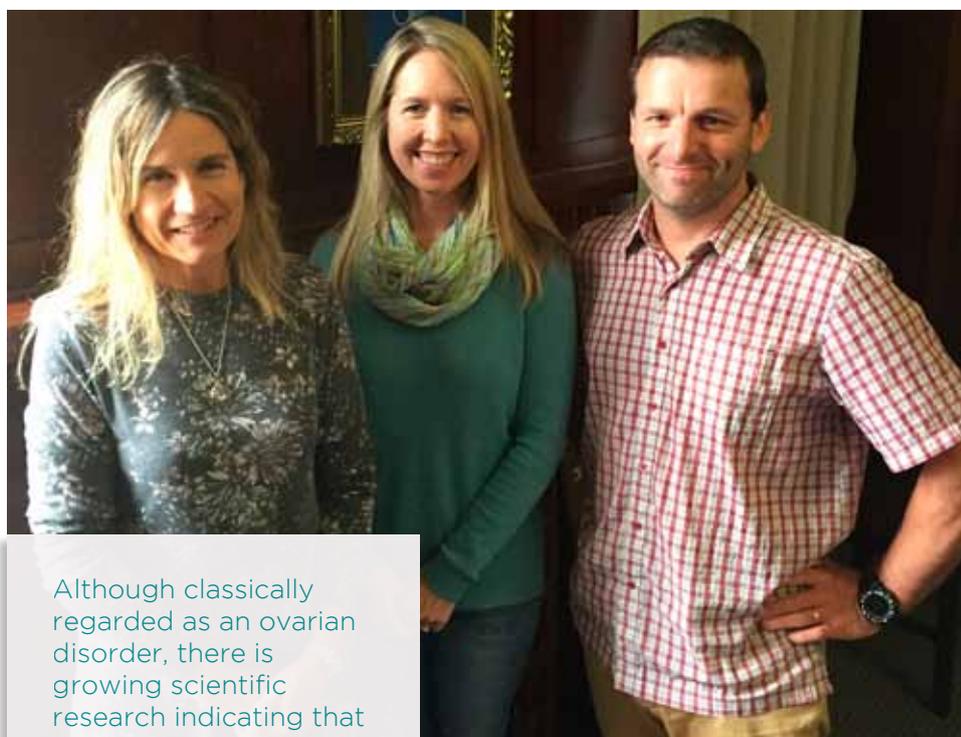
Dr Rebecca Campbell outlines her team's world-leading research into PCOS

Most people do not immediately think of the brain when they consider polycystic ovarian syndrome (PCOS), the most common endocrine disorder associated with infertility.

However, for a group of researchers in the Centre for Neuroendocrinology at the University of Otago, the brain has become the central focus of their research into how PCOS develops and results in reproductive problems.

PCOS is characterised by a failure to ovulate, which often leads to multiple ovarian 'cysts', and an excess level of androgens, typically thought of as male sex hormones. PCOS can also be associated with obesity and distressing overt symptoms such as excess body hair, male-pattern baldness, and acne. Although classically regarded as an ovarian disorder, there is growing scientific research indicating that the brain is a key player.

The function of the ovary is controlled by signals that come from the pituitary gland, which in turn, are controlled by the brain. A fascinating aspect of this system is that the brain can also listen to the ovary, much like a conversation between two people. In healthy individuals, this 'conversation' goes both ways and the brain and ovary can respond to one another appropriately. In PCOS, however, this conversation stops working effectively. Scientists have identified that when a woman has PCOS, her brain does not listen properly to the hormone signals



Although classically regarded as an ovarian disorder, there is growing scientific research indicating that the brain is a key player in polycystic ovarian syndrome (PCOS).

Above, from left: Associate Professor Christine Jasoni, Associate Professor Rebecca Campbell and Professor Greg Anderson.

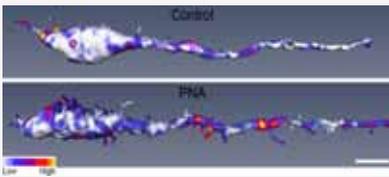
coming from her ovary. Just like in a conversation when one person keeps talking without listening to the other, unusual things happen. In the case of the brain-ovary conversation, a breakdown in communication results

in poorly regulated ovarian function and an overproduction of androgens. Discovering what causes the insensitivity of the brain to signals from the ovary and identifying the specific brain cells involved is important to determine how to restore two-way communication and better manage or cure PCOS.

Although these are difficult questions to assess in women, animal models of the syndrome are enabling researchers to probe deeper into the role of the brain in PCOS. Associate



Brain imaging can map the long axon 'wires' of specific brain cells to the cells in the brain that are known to be critically important in regulating ovary function and fertility.



These 'heat maps' indicate differences in the amount of communication that specific brain cells receive from other brain cells in PCOS-like (PNA) and fertile (Control) mice.

The cell from the PCOS-like brain has more spiny protrusions and warmer colours indicating more input from a particular signal

Professor Rebecca Campbell and her team have used brain imaging to discover specific neural circuits in the brain that are wired differently in a PCOS-like state. They have found changes in some neural circuits that help explain why the communication between the brain and the ovary in PCOS is impaired. This team of scientists are now using the latest tools in neuroscience research to alter the communication between these circuits to assess their specific functions in normal fertility and in PCOS-like conditions.

Although the primary cause of PCOS remains unclear, work in the Campbell laboratory supports growing scientific evidence that a high androgen environment in the womb can cause PCOS to develop later in life. They have discovered that changes in brain wiring occur early in development, after this high androgen exposure but before

PCOS symptoms even occur. This suggests the altered sensitivity in the brain might be the primary cause of PCOS. However, they have also found that normal brain wiring and ovary-brain communication can be restored in adulthood with drugs that block androgen signals. The group have recently received funding from the Royal Society Marsden Fund to address critical questions about the role of androgen excess in the female brain in development and adulthood.

To probe further into the origins of PCOS and how metabolism plays a role, Associate Professor

Campbell has recently teamed up with developmental neurobiologist, Associate Professor Christine Jasoni, and metabolic network expert, Professor Greg Anderson. With their combined expertise, the team hope to determine how androgen blockers can be harnessed to promote better brain-ovary communication to ultimately reverse PCOS symptoms and restore healthy fertility in women. The team are also passionate about scientific outreach and communicating about the latest developments in PCOS research to patients and those on the front line of treatment.

We invite you to attend Fertility Support Series

FERTILITY NZ IS A REGISTERED CHARITY, committed to supporting all people with fertility issues at all stages of their journey and beyond.....

Fertility Support Series run over three evenings in consecutive weeks. This is an opportunity to meet others experiencing infertility, gain support and coping strategies in an informal and relaxed setting.

Groups are run by experienced facilitators. Couples or singles who are yet to have children are welcome*. Research demonstrates psychological and physical benefits of in-person support.

FOR MORE INFORMATION OR TO REGISTER FOR FERTILITY SUPPORT SERIES, email aucklandsupport@fertilitynz.org.nz

* Do you already have a child or children and are trying for more? We have a specialised support network for people with secondary infertility. Email secondarysupport@fertilitynz.org.nz or visit our website www.fertilitynz.org.nz

2018 DATES:

1: TUESDAYS
6, 13, 20 MARCH

2: TUESDAYS
5, 12, 19 JUNE

3: TUESDAYS
16, 23, 30 OCTOBER

TIME:
7.30 - 9.30PM

VENUE:
REMUERA, AUCKLAND

COST: DONATION OF \$15PP
(\$30 PER COUPLE), COVERS ALL 3 SESSIONS

BECOME A FNZ MEMBER

GAIN SUPPORT, HOPE & FRIENDSHIP.

"I was feeling isolated from my usual support networks and it was so good to meet people who really understood what we were going through. It is the first time I have done something like this but everyone was relaxed and friendly. I am still in contact with all the people in our group and it has been great to have their ongoing friendship and support. It is one of the most positive things I have done for myself in a long time. Thank you."



 Fertility NZ  @FertilityNZ

0800 333 306 www.fertilitynz.org.nz



noticeboard

Support
Group
Dates

**AUCKLAND:
FERTILITY SUPPORT SERIES
(3 SESSIONS)**

Tuesday 6th 13th, 20th March
Tuesdays 5th 12th, 19th June

**AUCKLAND:
PREGNANT AFTER
FERTILITY TREATMENT**

Sunday 4th March
Sunday 8th April
Sunday 6th May
Sunday June TBC

AUCKLAND: CASUAL COFFEE

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

**AUCKLAND:
SECONDARY INFERTILITY**

Sunday 25th March
Sunday 29th April
Sunday 27th May
Sunday 24th June

**AUCKLAND:
SINGLE MOTHERS BY CHOICE**

Sunday 25th March
Sunday 29th April
Sunday 27th May

HAMILTON

Saturday 17th March
Saturday 21st April
Saturday 19th May
Saturday 16th Jun

HAWKES BAY

Sunday 15th April
Sunday 17th June

WELLINGTON

Tuesday 3rd April
Tuesday 15th May
Tuesday 26th June

NELSON

Tuesday 27th March
Tuesday 17th April
Tuesday 29th May
Tuesday 19 June

CHRISTCHURCH

Tuesday 27th March
Tuesday 24th April
Tuesday 22nd May
Tuesday 26th June

DUNEDIN

Tuesday 6th March
Tuesday 3rd April
Tuesday 1st May
Tuesday 5th June

INVERCARGILL

Tuesday 6th March
Monday 9th April
Thursday 3rd May
Wednesday 6th June

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)

secondariesupport@fertilitynz.org.nz

(Secondary Infertility)

singlewomensupport@fertilitynz.org.nz

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