



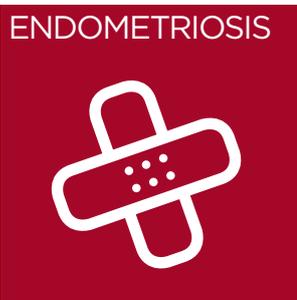
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THE Dandelion

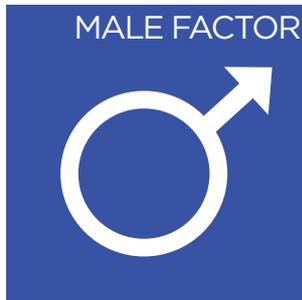
THE NEWSLETTER OF FERTILITY NEW ZEALAND, A REGISTERED CHARITY SUPPORTING PEOPLE WITH FERTILITY ISSUES

AUGUST 2015

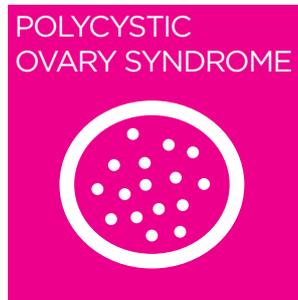
Did you meet the Usual Suspects?



ENDOMETRIOSIS



MALE FACTOR

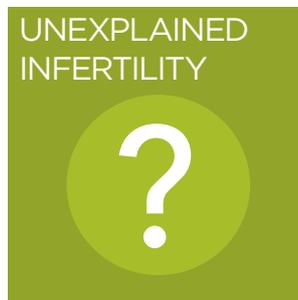


POLYCYSTIC OVARY SYNDROME

The annual Fertility Week campaign gave New Zealanders a chance to learn more about fertility – and the leading causes of infertility.



RECURRENT MISCARRIAGE



UNEXPLAINED INFERTILITY



Entitled *Fertility Week: Meet the Usual Suspects*, the campaign focused on Endometriosis, Male Factor Infertility, Polycystic Ovary Syndrome, Recurrent Miscarriage and Unexplained Infertility.

During Fertility Week, 11–17 May, we held Roadshow events in Auckland, Wellington, Hamilton, Christchurch,

Dunedin and Gisborne. Attendees heard a presentation on the 'Usual Suspects', which was followed by a Q&A session.

A series of webinars was also held, with a different 'Suspect' featured each weeknight.

There is a wealth of information still available on www.fertilityweek.org.nz. If you missed the webinars, you can watch the recordings of them too.

Now we are looking forward to Fertility Week 2016!

Continued on page 2 ▶

INSIDE THIS ISSUE

- A word from the President
- About Fertility NZ
- Fertility Week 2015 overview
- The Other Half – one man shares his perspective on the fertility journey
- Dr Andrew Laurie explains Preimplantation Genetic Diagnosis
- Fertility Clinic Survey: You spoke and we listened
- ACART & ECART: Who are they and what do they do?
- Noticeboard

"My part in our fertility journey"
PAGE 3



PAGE 5
Our Clinic Survey results: speaking volumes





Welcome Notes

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

This year's Fertility Week campaign with the theme: *Meet the Usual Suspects* has been and gone in the last month. It was centred around the major causes of infertility in New Zealand to raise awareness of Endometriosis, Male Factor Infertility, Polycystic Ovary Syndrome, Recurrent Miscarriage and Unexplained Infertility. These 'Usual Suspects' were explained, together with a clear distinction of 'what is normal and what is not'. Our board members stepped up to the plate and presented the roadshow across the country and we had guest speakers running our daily webinars. The webinars are now available for viewing at www.fertilityweek.org.nz.

Infertility is a hard journey no matter what your circumstances. One thing we have learned from our annual running of Fertility Week is that people on this journey really appreciate hearing other people's stories and advice. In this edition we are lucky to have one

of our consumers who spoke during Fertility Week share their story. Craig Berry shares his story from a 'Male Factor' perspective. It is great to read another perspective on the trials and tribulations of fertility treatment.

Myself and two other board members have just returned from the GP Conference in Rotorua over the weekend. We have been spreading the word amongst the 1000+ attendees hoping to educate them of who we are and what we offer. We had great feedback and will definitely be going back.

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

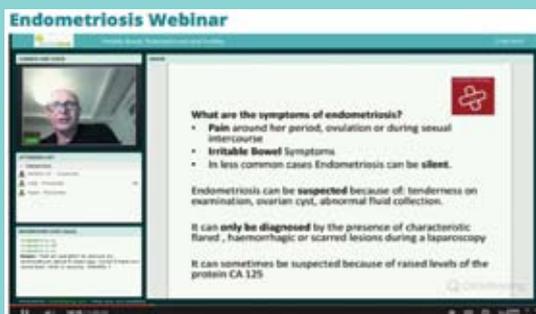
FertilityNZ has a vision of a 'fertility friendly' and fertility-aware New Zealand where:

- 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 Week 2015

◀ From page 1

Thanks to all those who made Fertility Week possible, particularly our sponsors, roadshow speakers and medical advisors, webinar presenters and information contributors. As usual, thanks go to our Executive Committee and Regional Support volunteers, who keep this organisation running. A final and very special thanks to all the people who so generously shared their own journeys with the 'Usual Suspects' in order to help others.



Above: Fertility Week on show at the Goodfellow Symposium in March, Nicola Bitossi mans the desk.

Left: View our webinars at www.fertilityweek.org.nz



Craig Berry with wife Andrea and daughters Amelia (4) and Harper (17 months).

PHOTO: MINK PHOTOGRAPHY

The Other Half

My Part in Our Infertility Journey

By Craig Berry

We had moved back to New Zealand from our OE and were primed to start our life here. We always thought we would have trouble, as my wife was previously suspected to have PCOS. We figured that we needed to start soon as both of us were keen on having children sooner rather than later.

Time went on and not a hint of success, my wife got the ball rolling with IVF. Unsurprisingly, I needed to get a sperm count. It seemed embarrassing

back then, and still does a little, but pales in comparison to the tests, prodding and poking my wife has endured.

Asking for the test was less embarrassing than getting the sample. Working longish hours combined with the opening times of the lab resulted in a narrow window for producing the sample. Turns out I needed to do it at work, just after my colleagues left. Not ideal circumstances for encouraging an erection. Afterwards came the doubts

over the sample, is that enough?

Next step, get it to the lab, traffic not too bad, although there was that pesky Toyota, whose driver was in a world of their own. Pull into the car park, doors still open, specimen delivered. Feeling awkward, I handed the warmish sperm sample over, "it's ok" I tell myself, as my face gets warm, "they do this all the time". All done, roll on to our fertility specialist appointment.

Then came the e-mail, volume 2.8mLs vs normal of 2 mLs, count 2 million vs normal of greater than 20 million, motility 30%, normal 50%, morphology 0%, panic sets in, 2 million is pretty bad based on the average it displayed. I thought I was fine and it was my wife with the fertility issues. I called my wife to share the news, confused and with a little bit of unease. I e-mailed the doctor, apparently they didn't do a morphology as the count was too low, that put me slightly at ease. Now ▶

◀ focusing on the count/motility, they were fails by all accounts.

In the meantime my wife had discussed the results with her doctor and I was relieved to hear that “stress” can affect the results, that must be it. I relayed the sample gathering story and felt relief that I could re-do the test, this second attempt was less stressful. Got the e-mailed results, count, 2 Million, crap, motility 20%, that was less than last time. It started to sink in, I was defective. The last grasp of hope was at the fertility clinic, no stress, a better environment, magazines, videos, sorted. Again the count was low but the motility was up, (by now I had a better understanding of the importance of motility, so took some solace in that).

An FSH test came back elevated and high testosterone, this was confusing, but the upshot was this could be a reason for my low count, but the downside could result in fertility issues in a son. I know I was getting ahead of myself with this thought, but back then I couldn't have imagined the extent of our wait.

With this new piece of the puzzle we had a discussion with the fertility

specialist about my wife's likely PCOS and my persistent low count. Was there anything I could do to up the quantity and quality of my sperm? IVF was the answer, but they also offered a new vitamin supplement focused on male reproductive health. If I can take this and we can have kids, we can put this whole sorry saga behind us. If only it were that simple – the whole IVF process can be a cruel lottery at times.

Even though my low count came as a bolt from the blue, I believe this actually helped my wife and I through the fertility journey. We were “fortunate” that no one half was to blame. I couldn't write it off as being all my wife's fault and leave all the hard decisions and supplementary procedures/tests/pills up to her. Being a factor in our infertility meant being more involved in the processes, it applied a level of responsibility to try and negate my body's shortcomings. At times I wasn't as proactive as I could have been, but I figured my wife's tenacity balanced things out.

All said and done it took:

- Countless ultrasounds, IVF consults
- Acupuncture (for both of us)

“Being a factor in our infertility meant I was more involved in the processes than potentially I would have been.”

- Numerous naturopath consults
- A small pharmacy of supplements
- 3 Lipiodol flushes
- 3 laparoscopy procedures (turns out it wasn't PCOS but stage 3 endometriosis)
- Daily IVF drug injections
- Colorado protocol X2 (something the wife found)
- Hypnotherapy for the wife (to retain her sanity during her pregnancy)
- 4 IVF cycles
- 5 embryo transfers
- 5 “two week waits” followed by the dreaded phonecall
- One chemical pregnancy
- Pregnancy at last, but ...
- A visit to Women's assessment unit at National Woman's with abdominal pain at 6 weeks
- Another visit to the assessment unit with bleeding at 8 weeks

Preimplantation Genetic Diagnosis

Dr Andrew Laurie, Canterbury Health Laboratories, Christchurch.

What is preimplantation genetic diagnosis, and who is it for?

Preimplantation genetic diagnosis, known as PGD, is a treatment option for couples who are at risk of having a child with a severe genetic disorder, such as cystic fibrosis or Huntington's disease. Until recently, such couples who wished to avoid having an affected child could undergo a pre-natal test to find out if their pregnancy would result in a child with the disorder, and they may then be faced with the difficult decision to terminate the pregnancy. PGD allows embryos that are not affected with the disorder to be identified before the pregnancy is established.

It should be noted that most

couples that undergo PGD do not have fertility problems. However, PGD must be performed as part of an in vitro fertilisation (IVF) cycle, so their treatment experience has much in common with that of fertility patients.

What does PGD involve?

Couples for whom PGD is an option are usually referred to the fertility clinic by a genetic counsellor. The clinic then arranges for the PGD testing laboratory to perform a PGD Feasibility Test which involves developing a strategy to test embryos for the presence of the specific disease-causing mutations carried by the couple. Once the PGD lab has confirmed that they have set



Cells being removed during embryo biopsy

up the testing strategy the couple are scheduled for their IVF cycle.

The IVF process for PGD is similar to a normal IVF cycle, but requires an extra step called embryo biopsy, where several cells from each developing embryo are removed for analysis. This enables identification of the embryos which would result in a healthy child that is not at risk of having the genetic

All this occurred before we were finally able to welcome our first daughter. For daughter number two the process was repeated, and fortunately, for our sanity and bank balance, she came around her first cycle, our fifth.

In a lot of the above, I say we, but in all reality it's a couple of minutes alone that constitutes the input for the male, the remainder is trying to be positive, strong (which I readily admit I failed at times), and encouraging from the side-lines of whatever your wife is currently planning, because at the end of the day you need to be a willing passenger in her hell bent determination to have a child.

What I call "The Other Half" or in fertility terms "Male Factor" may be half the reason my wife and I could not conceive naturally, but perversely the ability to have a 50% input into the solution is not possible. When you look at the poking, prodding and indignities of intimate procedures the woman has to endure, scoring the males actual input towards the final goal of conceiving a child at 5% would be generous.

Craig Berry

disorder carried by the couple. It is important to note that the removal of these cells for analysis does not affect normal development of the embryo.

After the PGD testing lab sends the results back to the fertility clinic, the transfer of one of the healthy embryos can be scheduled. Any other non-affected embryos may be kept frozen for transfer at a later date.

Is PGD publicly funded?

For couples who have a 25% or greater risk of having a child with a severe genetic disorder public funding is available, although there may be a waiting list to begin the treatment. There are some other criteria that must be met, and the funding is limited to two IVF cycles.

Dr Andrew Laurie is a Scientific Officer at Canterbury Health Laboratories, Christchurch, where he leads the PGD analysis team.

CLINIC SURVEY:

You spoke, and we listened!



Earlier this year, we conducted our first major survey of our Members' (and friends') experience with fertility clinics. The objective was to improve the experience at New Zealand fertility clinics, and the insights we gained were invaluable. Of particular value was the effort and thought which respondents put into the qualitative (open answer) questions – this has given us a really in-depth understanding of the clinic experience.

The majority of survey respondents were female. The length of time as a patient varied, but the most common bracket was 1–3 years. Slightly more than half of the respondents were past patients of a fertility clinic, with the remainder being current patients.

Overall, most respondents reported positive experiences with their clinics, however 34% of respondents did not have positive experiences with their clinic. The survey told us that a positive experience from a patient perspective is not only reliant on a "success" but also their interaction with the various departments and the support they receive from them. There was also much feedback around the diagnostic/pre-treatment phase and also support/communication between patient and clinic.

Fertility NZ will relay the following themes (along with clinic-specific data) to each NZ fertility clinic:

1. Clinics should effectively communicate all information to their patients to ensure the process is more transparent. This includes:
 - Clearer, thorough but concise information, which considers all options including alternative therapies (not just IVF) their advantages, disadvantages, side effects and procedures. Detailing all tests required prior to commencing treatment.

- Encouraging doctors to fully explain options/proceedings and then making sure patients truly understand what is happening.
- Ensuring patients have sufficient time during appointments to ask questions.
- Detailed background histories should be recorded with a more holistic view on each case.

2. All correspondence must be undertaken in a sensitive, empathetic and respectful manner, which includes tone of voice and (if applicable) both parties should be included in discussions.

3. Patient-clinic communication should be readily available and of appropriate frequency. This should be via a channel of a patient's choosing. Follow-ups after tests and procedures, especially failed cycles, are paramount to patient experience.

4. Continuity of care between all departments is essential to patient experience and this includes consistency of information given.

5. Clinics need to ensure patients are treated as individuals. Files should be thoroughly revised before each consult and any correspondence, to ensure patients feel valued and respected.

6. Counselling services and their availability to patients could be improved.

Thank you to everyone who took the time to complete the survey. Following a strong response, we plan to run these surveys every year. Fertility NZ Members will be informed of the next survey via email (if you're not yet a member, register today at www.fertilitynz.org.nz/register).

ACART & ECART

Who are they and what do they do?

By Nikki Horne

ACART – an overview

The Advisory Committee on Assisted Reproductive Technology (ACART) has been established to formulate policy and advice specific to New Zealand within the controversial field of human assisted reproductive technology.

ACART is established under section 32 of the Human Assisted Reproductive Technology (HART) Act 2004.

ACART's two key functions are to:

- Provide advice to the Minister of Health.
- Issue guidelines and provide advice to the Ethics Committee on Assisted Reproductive Technology (ECART) on procedures and research requiring case-by-case ethical approval.

ACART's work is guided by the principles of the HART Act:

- The health and wellbeing of children born as a result of an assisted reproductive procedure or an established procedure should be an important consideration in decisions about that procedure.
- The human health, safety and dignity of present and future generations should be preserved and promoted.
- While all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application, and the health and wellbeing of women must be protected in the use of these procedures.
- No assisted reproductive procedure/research should be performed on an individual unless the individual has made an informed choice and given informed consent.

- Donor offspring should be made aware of their genetic origins and be able to access this information.
- The needs, values and beliefs of Māori should be considered and treated with respect.
- Different ethical, spiritual, and cultural perspectives should be considered and treated with respect.

ECART – an overview

The Ethics Committee on Assisted Reproductive Technology (ECART) considers, determines and monitors applications made by fertility clinics for certain assisted reproductive procedures and human reproductive research.

ECART can only consider applications for procedures that the Advisory Committee on Assisted Reproductive Technology (ACART) has issued guidelines and advice for. Established

procedures do not need ethical approval from ECART. (See the table below.)

My Connection to ACART

For the past 5 years I have been the consumer representative on ACART. My own fertility journey started some 10 years ago, when my husband and I discovered that the only way we could have a family was via IVF ICSI. The next 4–5 years were the most distressing, challenging and heart wrenching of our lives. We went through 5 cycles of ICSI, falling pregnant every time, but then miscarrying. Finally on cycle 6 we managed to hold on to this baby. Madison is now 7 years old. We decided to try again very quickly after having our first daughter as we thought it might take another several years to have a sibling for her. We were very shocked when the first cycle was successful.

ECART considerations for review

ECART review required	No ECART review required
Clinic-Assisted Surrogacy	Artificial Insemination
Donation of Eggs or Sperm between Certain Family members	Collection of Eggs or Sperm for the Purposes of Donation
Embryo Donation for Reproductive purposes	Egg and Embryo Cryopreservation
Creation and Use, for Reproductive Purposes, of an Embryo Created with Donated Eggs and Donated Sperm	In Vitro Fertilisation (IVF)
Pre-implantation Genetic Diagnosis (PGD) with Human Leukocyte Antigen (HLA) Tissue Typing	Ovarian Tissue and Sperm Cryopreservation
Research on Gametes and Non-Viable Embryos	Intra-cytoplasmic Sperm Injection (ICSI)

ECART's work is guided by the HART Act principles, as listed above under ACART.



Nikki Horne with Madison and Brooklyn.

Brooklyn is now 6 years old and keeping us on our toes.

Throughout our infertility journey we turned to Fertility New Zealand for support. We went to a contact support group and found the process incredibly supportive. It was so nice to find people who truly understood what we were going through and to be able to talk honestly about how we felt without being judged and given well meaning, but at times, quite hurtful advice. I got so sick of hearing “you just need to relax a bit and stop focusing so much on it and then it will happen naturally”.

Having taken part in a contact group, I then decided to get involved with FNZ and join the Auckland Committee. Six years ago I was approached to apply to become a member of ACART. I had heard of ECART and ACART, but in our situation we didn't have to go through the ethics process. I did however support a few friends going through surrogacy applications, so was generally aware of their functions.

I was appointed by the Minister of Health to ACART for an initial term of 2 years. I was absolutely terrified of what I had got myself into. Having read the bio's of the other members on the committee, including a Dame, professors, lawyers, fertility specialists, etc., I struggled to put my

It is important that reproductive technology is considered from medical and ethical perspectives and that the outcomes safeguard the health and well-being of children born as a result.

own bio together. I got to “mother and housewife from Takapuna”... Having said that, as my husband kept pointing out, I had practical real life experience of infertility, so I hoped that I could make a valuable contribution. From the first meeting, I must say I have always felt like an integral and important part of this committee. The Secretariat from the Ministry of Health, who support ACART, are exceptional with educating along the way on how the Hart Act & Hart Order work, what the functions are, and successive chairpersons have always been inclusive with ensuring views for all members of the committee are taken into consideration. There have been some very robust and ethically challenging discussions, but it has always been done professionally and respectfully.

Although others are far more academic and experienced in their fields, I have always felt, that being able to articulate from the end user perspective is key to the work that we do. We can debate from ethical, scientific and other perspectives, but we must always keep in mind how it affects the consumer and the human beings who have to live by our recommendations and guidelines. Having to advocate and represent consumers can be difficult, because naturally I have my own personal opinions on subjects, but as a representative I must always keep in mind that there is a broad spectrum of views. I have had many sleepless nights working through all the ethical dilemmas that come from this area.

My greatest frustration has been trying to get more consumers involved in the consultation process. A lot of people have firm views about things, but shy away from putting in submissions when things are being debated. ACART tries as much as possible to write their consultation documents in lay-person terms, so everyone has the ability to understand what can be quite complex subjects, and have the opportunity to put forward their own views. It is important for those that do have views to try and get involved. All voices are heard and consumer views are given a lot of weight when we do consultations, so the greater involvement from the public the better. The process is a very fair and robust one.

My time as the Consumer Representative will come to an end this year. After 5 years, I can truly say it is one of the most satisfying, interesting and challenging experiences I have been involved in. Technology, particularly in this area of medicine, is fast moving and can create some wonderful opportunities for people - without it I probably wouldn't be a mother - however, it is equally as important to ensure that this technology is researched properly, considered from medical and ethical perspectives and that the outcomes safe guard the health and well-being of children born as a result.

noticeboard

Wellington Support Group

We're changing the way we offer support to our members! Instead of the Saturday Coffee and Chats, we will now be running 6-weekly evening events at the Southern Cross. We will be inviting speakers on a variety of topics to informally share their knowledge. See you there!

Support Group Dates

AUCKLAND

*Tuesday 21 July
Tuesday 18 August
Tuesday 15 September
Tuesday 20 October*

AUCKLAND CONTACT GROUP

*Tuesday 6, 13 and
20 October*

HAWKES BAY

*Sunday 13 September
Sunday 6 December*

WELLINGTON

*Wednesday 1 July
Wednesday 12 Aug
Wednesday 23
September*

CHRISTCHURCH

*Tuesday 28 July
Tuesday 25 August
Tuesday 22 September
Tuesday 27 October*

DUNEDIN

*Tuesday 7 July
Wednesday 5 Aug
Tuesday 1 September
Tuesday 6 October*

Wellington Support and Connect

Come to our regular informal evening get-together and meet other local women who are dealing with all aspects of infertility. Hear from speakers and talk to members of the Wellington Fertility NZ Committee.

6.30pm–8.30pm on Wednesday evenings, every 6 weeks at the Southern Cross, 39 Abel Smith St, Wellington. Look for the table with the gerbera flower!

Contact wellingtonsupport@fertilitynz.org.nz for more information.



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

Wellington

wellingtonsupport@fertilitynz.org.nz

Nelson – coming soon

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

This material is supported by way of an educational grant from Canterbury Health Laboratories. 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 Canterbury Health Laboratories.

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