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THE Dandelion

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

APRIL 2017

The evolution of 'infertility'

Jane Adams writes about how 'infertility' has evolved in New Zealand and her academic and personal connection with the subject

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RIGHT: Embryology, mid 1980s at National Women's Hospital, using a converted baby incubator as a portable work station.



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Remember, our support network exists to help you on your journey

How did infertility – once considered a private 'woman's problem' and still shrouded in great secrecy in mid-twentieth century New Zealand – become the subject of ongoing, intense public scrutiny and discussion three decades later? That is a central question I have explored in my University of Otago PhD thesis in History and Law.

Focusing primarily upon medico-legal responses to infertility, I examined how these responses were transformed over time, due to the introduction of various assisted reproductive technologies ('ART') such as IVF. Changing family forms and broader social reform movements in

New Zealand, such as women's rights and human rights movements from the 1970s, also contributed to these changing understandings of what it meant to be infertile and who should be allowed to access infertility treatment.

Lesbian and single women, for example, became eligible for publicly-funded infertility services from the mid-1990s as a result of human rights law developments. This development was one never contemplated by mid-century doctors, for whom infertility was only seen as a problem that could be experienced by heterosexual couples – and strictly married ones at that.

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Advocates of genetic screening





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.

Thanks to a wonderful network of volunteers, we have a great coverage of support groups throughout the country. Our support groups and events are a safe space to gain support and connect with others 'in the same boat'. Many of these groups have their own closed Facebook page which is used to connect between meet-ups. New people are always welcome – see the back page for a group or event near you.

Fertility NZ held its AGM in

November and our current Executive Committee, which governs the organisation, is listed below. Together with the 20+ volunteers who run support groups around the country and two employees, Fertility NZ's Executive Committee is committed to providing information, support and advocacy to our community.

On page 1 you will read an article contributed by Jane Adams. Jane volunteers as one of our Dunedin support group facilitators. She recently completed her PhD on the medico-legal history of infertility in New Zealand. I found it interesting to reflect on the relatively recent changes in philosophy as well as medicine.

Genetic carrier screening is an issue which has been brought to the fore by Fertility NZ Members Waverley and Peter Waring. Neither Peter nor Waverley have any family history of genetic disorders, yet their son Flynn was born with Cystic Fibrosis. They encourage people undergoing fertility treatment to have screening incorporated into their treatment programme. Read more on page 4.

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
Anita Killeen – Vice President
Cate Curtis – Treasurer
K-J Dillon – Secretary

Corporate / Medical Members

John Peek
Jo Barnett

Regional Representatives

Karina Wong (Auckland)
Juanita Copeland (Christchurch)

The evolution of ‘infertility’

◀ From page 1

In order to track shifting ideas about infertility and family formation, I examined both medical and non-medical solutions to infertility, including ‘closed stranger’ adoption, 1960s fertility drugs, donor insemination, IVF, egg donation, surrogacy and intracytoplasmic sperm injection (‘ICSI’).

I also traced how infertility featured in New Zealand’s politico-legal discussions, ranging from adoption and divorce law cases to the emergence of ART policy and legislation – and particularly, the Parliamentary debates over the Status of Children Act 1987 (the only legislation passed on ART in the 1980s), later followed by the Human Assisted Reproductive Technologies Act 2004.

Infertility researchers in Melbourne, Australia were at the forefront of world-leading developments in ART, and I also have tracked the flow of medico-legal ideas, technologies and people between Australia and New Zealand.

The role of support

Infertility support organisations have consistently played a key role in helping raise public awareness of infertility, my research shows. By the early 1980s, ‘closed stranger’ adoption – a popular non-medical way for infertile couples to form their families from the 1950s – had become a less viable solution, due to a shortage of babies available for adoption.

Following international trends, regional infertility support groups were established around New Zealand from the early 1980s. Resolve New Zealand, for example, was based in Wellington and modelled on a United States society formed in Boston in the mid-1970s.

Establishing an IVF programme within New Zealand and raising public awareness of infertility was an early priority of these groups. Sympathetic local media regularly drew attention to the plight of infertile couples who travelled to Melbourne for IVF treatment in the 1980s (Australia’s first and the world’s third ‘IVF baby’ was born in Melbourne in mid 1980).

New Zealand’s first ‘IVF baby’, born in Christchurch in March 1983,



LEFT: Organising the first seminar of the Auckland Infertility Society, from left, Annette Ellis, Dr Freddie Graham, Joi Ellis.

was conceived following the parents’ participation in the Melbourne Royal Women’s Hospital IVF programme – an event which sparked further public debate over whether New Zealand needed its own IVF programme.

‘Secret’ research

When in August 1983, news of Dr Freddie Graham’s so-called ‘secret’ IVF research at Auckland’s National Women’s Hospital was revealed and the programme was temporarily suspended, members of the recently-formed Auckland Infertility Society campaigned effectively in support of Graham’s fledgling programme along with other professionals – speaking openly to the media about their infertility experiences and undertaking fundraising for IVF equipment.

Both support group members and health professionals at this time frequently depicted infertility as a physical ‘disease’ with psycho-social dimensions. Associating infertility with ‘disease’ was, I show, a new development in medical discussions (reflecting medical interest in ‘treating’ infertility caused by tubal disease by using IVF), and one which added weight to campaigns for public health funding for infertility services.

Effective campaigns

The ongoing close association between health professionals and infertility organisations has helped contribute to the effectiveness of their infertility awareness campaigns.

From the late 1980s, infertility has also been characterised as a ‘disability’ due to developments in human rights and health and disability law.

My academic interest in this topic was sparked by my own experiences as an infertility patient, firstly in Melbourne (where my older son was conceived as a result of IVF-ICSI treatment at Monash IVF) and then in Dunedin, where we undertook IVF treatment with Professor Wayne Gillett’s team at Otago Fertility Services (as it was then known). My husband and I were then fortunate to conceive our younger son naturally, after an unsuccessful frozen embryo transfer cycle. Researching the experiences of women who underwent infertility treatment in earlier periods – including those who participated in earlier drug and IVF trials at a time when the success rates were lower and the treatment regimes particularly intensive – has made me feel grateful for the relative advances in twenty first century ART.

Jane Adams is co-facilitator of our Dunedin Support Group, which meets each month for an informal coffee and chat. Thanks very much to Jane for finding the time to share her fascinating research with The Dandelion. We wish Jane the best of luck for transforming her thesis into a book, and trust she will enjoy her graduation in May. – Nigel



Making an informed choice

Genetic carrier screening may hold important information for people trying to conceive naturally and through ART. Peter and Waverley share their heart breaking story, in the hope it will help other families.

Could you have a high chance of passing a severe genetic condition on to your child? If you haven't had a genetic carrier screening test, the simple answer is 'Yes'.

This is the message we want to share with other parents after the shock diagnosis of our second son Flynn with cystic fibrosis. We had no knowledge of recessive genetic conditions and no idea that we had a high chance of having a child with a genetic condition. We are both healthy, our first son Luke is healthy. We had all the usual pregnancy scans, blood tests and chromosome abnormality screening and had no idea we could be at risk.

Flynn arrived on his due date, a gorgeous, alert little boy. We were told everything had gone well, he was healthy and we could go home

and enjoy being a happy family of four. We had a wonderful first two weeks with him and Luke was so excited to have a baby brother. Unfortunately our happiness wasn't to last. Two weeks after he was born we received devastating news from our midwife – Flynn's Guthrie Heel Prick Test indicated that he was likely to have cystic fibrosis, an incurable, life shortening condition. Following a harrowing few days of further tests and appointments, his diagnosis was confirmed and our world fell apart. We struggled to come to terms with learning how to do his daily physiotherapy, give enzymes and salt before every feed and the regular hospital visits. The grief of losing the healthy child you thought you had and the reality that we were now likely to

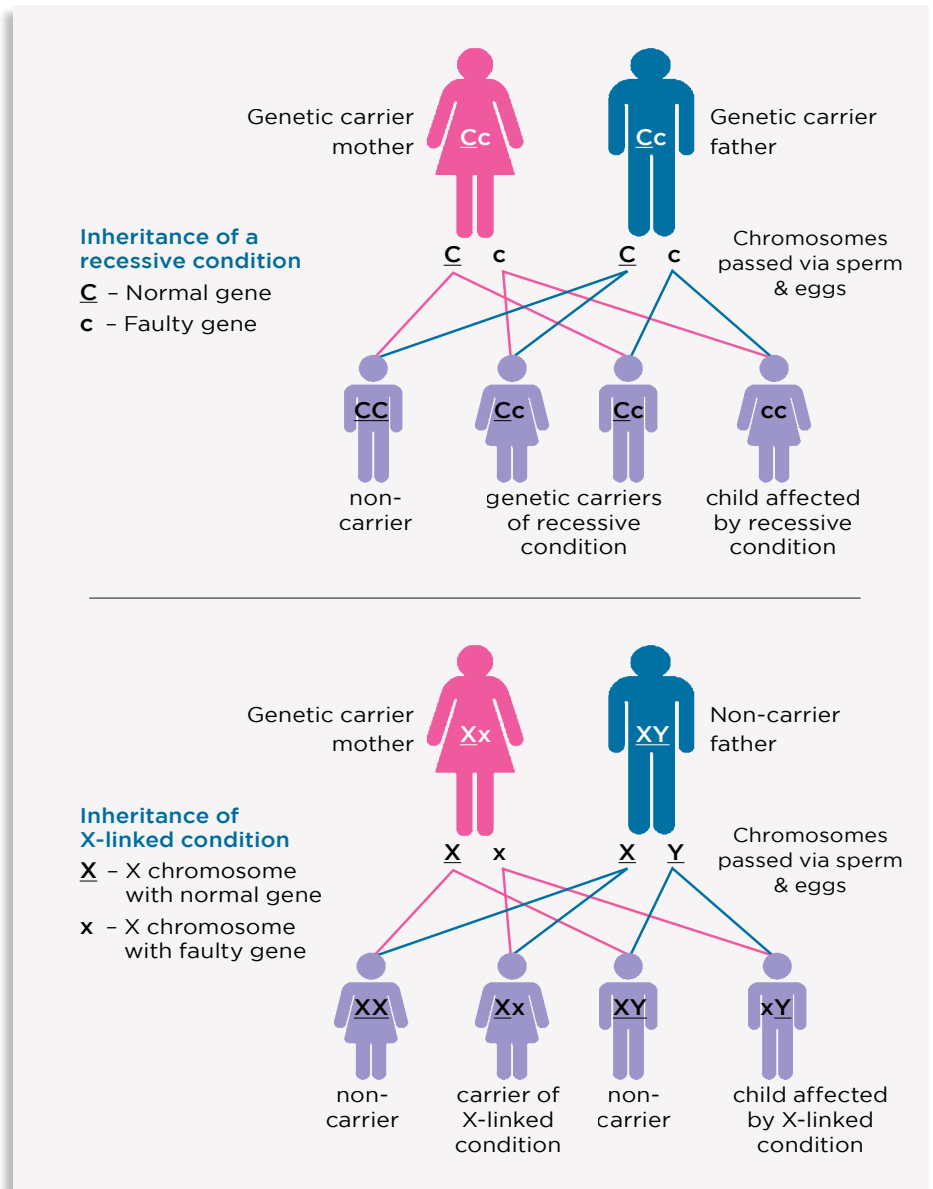
have to watch our much loved son die slowly from irreversible lung damage was, and continues to be, truly heart breaking.

By far, the most difficult aspect of Flynn's diagnosis was the realisation that a simple blood or saliva test would have given us the opportunity of having a child without cystic fibrosis. After searching cystic fibrosis on the internet, we very quickly realised that we should have had the opportunity to have a genetic carrier test before pregnancy. This would have told us that we had a high chance of having a child with a severe genetic condition. We then could have accessed free, government funded pre implantation genetic diagnosis (PGD) IVF where only unaffected embryos without the condition are selected.

Genetic carrier screening has been routinely offered internationally in America for over 16 years and in Australia for over 10 years, however there has been no genetic screening routinely offered in New Zealand. As the life impacts for both the parents and the child are so severe, we felt it was important to advocate for genetic carrier testing to be routinely available in New Zealand and to help raise awareness of the testing so other parents have the opportunity to make informed choices. Genetic carrier screening was first made available privately by Fertility Associates in May 2016, 11 months after Flynn's birth.

As the testing is new to New Zealand, public awareness is still very low. We want to share our experience and information about genetic carrier screening with the Fertility NZ community in the hope that it will help another family and give prospective parents the opportunity to make an informed choice about the test.

In addition to our personal story, we also want to be able to share some more detailed medical information and expert opinion on carrier screening. We were lucky enough to speak with medical professionals from the Victorian Clinical Genetics Service and The University of Auckland, School of Medicine about genetic carrier screening. Here's what they shared with us.



Genetic carrier screening – a medical perspective

For parents wanting to minimise their chance of having a child with a serious genetic condition, genetic carrier screening is an important option to consider, explains Dr Alison Archibald, Associate Genetic Counsellor with the Victorian Clinical Genetics Service (VCGS), a not-for-profit organisation which has the most advanced genetic testing technology in Australasia.

VCGS has offered their testing services for over 10 years in Australia and their tests are now also available in NZ. Genetic carrier screening involves a simple test using blood or saliva, with the results indicating if an individual

or couple have a high chance of having a baby with one or more of the serious inherited genetic conditions being tested for. VCGS offers two carrier screening options. The Prepair test can identify if people are carriers for three common and severe genetic conditions, namely:

- **Cystic Fibrosis:** the most common, incurable genetic condition. 1 in 25 people are carriers.
- **Fragile X Syndrome:** the second leading cause of intellectual disability after Down Syndrome. 1 in 250 women are carriers.
- **Spinal Muscular Atrophy:** the leading genetic cause of infant mortality. 1 in 40 people are carriers. ▶



Flynn's current treatment takes two hours each day.

The Prepair Plus test includes these three conditions as well as almost 100 other rarer, but severe inherited conditions.

The main misconception about genetic carrier screening is that no known family history means you are unlikely to have a child with a genetic condition, however this is not the case explains Trent Burgess a Senior Scientist who works alongside Dr Archibald on Genetic Carrier Screening at VCGS. For example, research tells us that about 95% of parents who have a child with cystic fibrosis, do not have a known family history of the condition.

So how could you have a high chance of having a child with a serious genetic condition and not know? The secret lies in what is called recessive inheritance. "Carriers' of a faulty gene also have one healthy working gene which takes over, essentially hiding the existence of the

"We had no idea that we had a high chance of having a child with a genetic condition - no idea we could be at risk."

faulty one," explains Trent.

There are two types of recessive genetic conditions:

Autosomal recessive conditions occur when both parents carry a faulty gene and these are passed on to the child. For these conditions, carrier couples have a 1 in 4 (or 25%) chance of having an affected child every time they become pregnant.

X-linked conditions occur when a mother is carrying a faulty gene found on one of her X chromosomes. Each time the mother has a child she has a high chance (up to 1 in 2, or 50%) of

having an affected baby. Dr Archibald explains that carrier testing for Fragile X is indicated for women with irregular periods, fertility problems or early menopause, due to a condition called 'Fragile X-Associated primary ovarian insufficiency' which is common in female carriers of Fragile X.

Professor Peter Stone, Maternal Medicine Specialist at The University of Auckland, School of Medicine sees the introduction of genetic carrier screening technology as an opportunity for New Zealand couples to understand their personal chance of having a child with certain severe inherited genetic conditions. "It is important that patients understand which conditions they are being screened for and receive appropriate pre and post-test genetic counselling so they are well informed throughout the process," says Dr Stone.

Preconception – the best time to screen

The best time to have genetic carrier screening is preconception and this can be conducted at most New Zealand fertility clinics.

In New Zealand, individuals or couples who have a 'high chance' screening result are eligible for up to two rounds of free, government funded PGD IVF where only unaffected embryos are selected. There is also free, publicly funded 'cascade' carrier testing and genetic counselling available for the partner and family of anyone identified as a carrier.

If carrier screening shows you individually or as a couple have a 'high chance' result (and meet other criteria for public funding), then you are likely to be eligible for IVF using PGD. In this case, other CPAC criteria, such as having to wait 5 years if you have unexplained infertility, do not apply. Up to 1 in 270 couples can be expected to have a high chance result.

Implications for people considering egg and/or sperm donors

For prospective parents thinking about using donated eggs and/or sperm, it is important to understand what screening tests donors have had. "You

In New Zealand, a 'high chance' screening result means eligibility for up to two rounds of free, government funded PGD IVF where only unaffected embryos are selected.

may want to request that the donors undertake genetic carrier screening so you can understand the chance of your baby inheriting a recessive genetic condition," says Dr Archibald.

For us, having a child with Cystic Fibrosis continues to be a profoundly devastating experience, yet it was so easily avoidable with a simple test. We didn't have the opportunity to make an informed choice about genetic carrier testing, but it gives us some comfort to know that other families now have that gift of choice and a greater chance of a healthy child.

Common genetic conditions

- **Cystic Fibrosis (CF):** is an inherited condition that primarily affects the lungs and digestive system. Individuals with CF develop an abnormal amount of thick mucus within the lungs and gut. There is no cure. Individuals with CF have a shortened life span with lung failure being the major cause of death.
- **Fragile X syndrome (FXS):** is the most common cause of inherited intellectual disability. People with FXS can have developmental delay, learning difficulties, anxiety, autism, epilepsy as well as some physical characteristics. There is no cure for FXS.
- **Spinal muscular atrophy (SMA):** is a condition that affects nerves in the spinal cord and causes muscles to get weaker. Babies with SMA type 1 have weak muscles from birth and usually do not live past two years of age. There is no cure for SMA.

Public awareness of genetic carrier screening is currently very low and it is not yet routinely offered, so you may want to consider sharing this information more widely with friends and family who may be considering a new baby. Collectively, every conversation counts and we know just how life-changing this information will be for some families.

Genetic carrier screening is now offered by fertility clinics throughout New Zealand and at Ascot Radiology in Auckland. VCGS Prepair costs \$495-\$550. Prepair Plus is expected to

be \$900-\$1000. Further information is available at www.vcgs.org.au/tests/prepair and from your fertility specialist or obstetrician.

Postscript: Following Flynn's diagnosis we have had one round of PGD IVF and have three embryos without CF 'on ice'.

With thanks to Dr Alison Archibald and Trent Burgess from the Victorian Clinical Genetics Service and Professor Peter Stone from the University of Auckland School of Medicine for their contribution to this article.

New dates added due to demand: Tuesdays May 2, 9 and 16

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

2017 DATES:

- 1: TUESDAYS
28 MARCH, 4 & 11 APRIL
- 2: TUESDAYS
6, 13, 20 JUNE
- 3: TUESDAYS
10, 17, 24 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
Tuesdays 22 Mar, 4, 11 April
Tuesdays 2, 9, 16 May
Tuesdays 6, 13, 20 June

AUCKLAND
CASUAL COFFEE
Tuesday 21st March
Tuesday 18th April
Tuesday 16th May
Tuesday 20th June

AUCKLAND
SECONDARY INFERTILITY
Sunday 26th March
Sunday 30th April
Sunday 28th May
Sunday 25th June

AUCKLAND
SINGLE WOMEN
Sunday 5th March
Sunday 2nd April
Sunday 7th May

AUCKLAND
**PREGNANT AFTER
FERTILITY TREATMENT**
Tuesday 28th March
Tuesday 25th April
Wednesday 31st May
Tuesday 27th June

HAMILTON
Saturday 18th March
Saturday 15th April
Saturday 20th May

TARANAKI
Wednesday 8th March
Wednesday 12th April
Wednesday 10th May
Wednesday 14th June

WELLINGTON
Wednesday 5th April
Wednesday 17th May
Wednesday 28th June

NELSON
Tuesday 14th March
Monday 10th April
Tuesday 9th May
Tuesday 13th June

CHRISTCHURCH
Tuesday 28th March
Wednesday 26th April
Tuesday 23rd May
Tuesday 27th June

DUNEDIN
Tuesday 7th March
Tuesday 4th April
Tuesday 2nd May
Tuesday 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
secondariesupport@fertilitynz.org.nz
(secondary infertility)
singlewomensupport@fertilitynz.org.nz

Casual Coffee Group (Auckland)
casualcoffeegroup@gmail.com

Hamilton

hamiltonsupport@fertilitynz.org.nz

Tauranga

taurangasupport@fertilitynz.org.nz

Rotorua

rotoruasupport@fertilitynz.org.nz

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Hawke's Bay

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Wellington

wellingtonsupport@fertilitynz.org.nz

Nelson

nelsonsupport@fertilitynz.org.nz

West Coast

westcoastsupport@fertilitynz.org.nz

Christchurch

christchurchsupport@fertilitynz.org.nz

Central Otago

centralotagosupport@fertilitynz.org.nz

Dunedin

dunedinsupport@fertilitynz.org.nz

Pregnant following fertility treatment?

Pregnancy can be a challenging time for women who have been through the challenges of treatment, and/or spent years trying to conceive. Immense joy and gratitude can be accompanied by feelings of disbelief and anxiety. It can be difficult to relate to women who fall pregnant easily. We have a group which meet monthly in Auckland to provide positive support to women who are pregnant following fertility treatment. We also have a closed Facebook group for 'Pregnant After Fertility Treatment', open to all New Zealanders. For more information on the Auckland support group, or the Facebook group, email Karina on aucklandsupport@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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