



THE Dandelion

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

FEBRUARY 2014



AGE



TIMING OF SEX



WEIGHT



ALCOHOL



SMOKING

FertilityWeek

Be Fertility Fit

We are very excited to announce New Zealand's inaugural Fertility Week! In 2014, the theme will be Fertility Week: Be Fertility Fit.

Fertility Week: Be Fertility Fit is a public education campaign which will raise awareness of the impact of the following 'Fertility Fit Factors' on fertility:

- Age
- Timing of sex
- Weight
- Alcohol
- Smoking

At the centre point of Fertility Week will be its own dedicated website – www.fertilityweek.org.nz. Each weekday during Fertility Week, a Fertility Fit Factor will be featured,

including practical information and tips; along with a webinar by a fertility specialist. We will also feature our Members' stories – if you have a story to share about the impact of one of the Factors on your fertility, which would help educate others, please let us know!

Roadshow

In addition to the website, there will be a Roadshow during Fertility Week. The Roadshow will be an information session on maximising fertility and chances of conception (both naturally and through ART). Presented by Loula George, Director of Mother-Well, the

Roadshow will be an opportunity to gain an understanding of the control you have over your fertility, based on solid New Zealand research. The events will be free-of-charge, but you will need to register as there will be limited places!

Fertility Fitness checks

Fertility Fitness checks will be available free-of-charge at various locations during Fertility Week. See the Fertility Week website for more information. ►

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www.fertilityweek.org.nz

April 7-13,
2014

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Welcome Notes

Happy New Year and welcome to this fifth edition of *The Dandelion* newsletter from Fertility NZ.

The exploratory stages of our funding campaign have begun. During February, focus groups will be held around the country to brainstorm with our Members around what the Campaign could involve. This research will help form a survey which will be sent to all Fertility NZ Members. The survey results will be the building block for our campaign for increased fertility treatment funding. Make sure you are heard!

Fertility Week

Fertility NZ will be hosting New Zealand's inaugural Fertility Week from 7–13 April this year. The theme will be Fertility Week: Be Fertility Fit. It will raise awareness of factors impacting fertility. Be sure to check out www.fertilityweek.org.nz from 7 April!

AGM

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

Support groups

Fertility NZ is now running support groups in Hamilton and Gisborne. These are both very casual, 'coffee' groups and welcome new people! Our regional events calendar and contact details are outlined on the back page.

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

Fertility NZ's Executive Committee

Nigel McKerras – President, Treasurer
John Peek PhD – Secretary, Medical Representative

Medical Representatives

Margaret Merrilees
Dr Greg Phillipson

Other Corporate Members

Fiona McDonald

General/Consumer Members

DeAnne Brabant
Cate Curtis PhD
Loula George
Anita Killeen

Regional Representatives

Nikki Horne (Auckland)
Nicky Mackenzie (Wellington)
Hayley McManus (Christchurch)

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Fertility Week

Calendar: April 7–13, 2014

Monday 7 April

Age: impact of age on fertility

How late is too late? What if I'm running out of time? Does age affect male fertility?

- Free Fertility Fitness checks, nationally

Tuesday 8 April

Timing of Sex

Timing is everything, and knowledge of your fertile window is the area in which you can have the most control over your own fertility.

- Roadshow: Auckland
- Free Fertility Fitness checks, nationally

Wednesday 9 April

Weight

Being overweight or underweight can negatively impact male and female fertility. What is a safe BMI? Can nutrition improve my fertility and my future baby's health?

- Roadshow: Wellington
- Free Fertility Fitness checks, nationally

Thursday 10 April

Alcohol

Is alcohol safe when trying to conceive? Learn the impact of alcohol and recreational drugs on male and female fertility.

- Free Fertility Fitness checks, nationally

Friday 11 April

Smoking

The impact of smoking and other environmental toxins on your chances of getting, and staying pregnant.

- Free Fertility Fitness checks, nationally

Saturday 12 April

- Roadshow: Hamilton and Tauranga

- Free Fertility Fitness checks, nationally

Sunday 13 April

- Roadshow: Gisborne

For GPs and Health Professionals

We will be presenting 'Fertility Week: Be Fertility Fit' at the Goodfellow Symposium (March 22–23, Auckland). In addition to providing information to assist GPs in educating their patients, we will be offering Fertility Week posters and postcards to help raise awareness of infertility and spread the message about Fertility Week. If you would like posters for your local clinic (or community centre), email support@fertilitynz.org.nz or call 0800 333 306.

Becoming a **facilitator**

Lorraine Carpentier-Jones explains why she decided to become an Auckland Contact Group facilitator

"I decided to become a facilitator as I wanted to draw together mentoring skills gained from my background in tertiary education and latterly my life coaching skills, together with my own fertility experience so that I could help others find the support they needed. Given the isolation I had felt on my journey, I knew the value that the groups would provide to others experiencing infertility.

My journey through infertility, and adoption to becoming a mum was under the spotlight again recently. I was recounting my story to a newly-assembled group of women and men as first time co-facilitator at an Auckland Fertility NZ Contact Group. Retelling my story really brought it alive again, and made me realise how much we went through.

"Joining a support group and meeting others brings a sense of relief at being able to talk freely to people who understand how you feel."

As soon as I started talking I knew I had done the right thing in stepping up as a Contact Group Facilitator. It felt right using my skills, and importantly my experiences to help others.

I was able to share that I had not sought support when we needed it most, as I was concerned that we would be labelled, and this might prejudice us if we decided to look at other options. I later realised that this was not the case at all, it was just my way of dealing with what was going on in our lives. We needed support but we just didn't feel that we could reach out for it.

My husband and I have an 8 year old daughter who joined our family through adoption in the UK. It was a case of being in the right place at the right time that enabled us to adopt her when she was 3 months old.

Prior to adopting, our fertility journey consisted of several rounds of treatment.

The catalyst for stopping the treatment, in my case, was my health; it became a choice between my health, and our fertility treatment. At this point we felt as though we had nobody to talk to – and that was the hardest part of our journey.

We launched ourselves into the adoption arena, knowing very little. We started the process for international adoption and then with guidance from our Social Worker we converted to domestic adoption, not realising what underpinned her decision to persuade us to make this change.

We did a 6-day adoptive parent preparation course and finally we found support from others who were in the same situation. For the first time in our journey, I felt we had somebody who understood us. We made friends and the support was just what we needed. Eight months later we had finished our paperwork and having been approved to adopt, we needed a holiday so we came to New Zealand and also Australia. We had only been back in the UK for two weeks when we had a call from our Social Worker saying she wanted to see us about a possible match. We met her and saw the profile of our lovely daughter who was only three months old. After seeing her each day for two weeks, she finally came home to join our family.

Since moving to New Zealand we have joined a few adoption groups and meet regularly to swap our stories. Our children also enjoy the meetings as they have lots in common with the other children.

Infertility does not have to be a lonely time. Joining a Contact group can help you to connect with others who are experiencing the same thing as yourself. From my own journey, I had so many unanswered questions and felt that I had nobody to talk to who had experienced what I was going through. By joining a Contact Group those questions can be answered in a safe space.

I feel that joining a support group and meeting others brings a sense of relief at being able to talk freely to people who understand how you feel.



Lorraine Carpentier-Jones with her daughter

If you are thinking about becoming a facilitator, you need to be comfortable with your own journey and strong enough to guide others. You may or may not have had success from fertility treatment – ideally, the two facilitators have had different experiences. Fertility NZ holds facilitator training sessions, run by experienced counsellors and technical fertility experts. Contact Groups are a very supportive environment and I have found being a facilitator a rewarding experience.

I feel very fortunate that Fertility NZ have given me the chance to train as a facilitator, and made me so welcome in their community."

Wanted: Christchurch Committee Members

Fertility NZ's Christchurch Committee is currently seeking new members. The Christchurch Committee plans (and assists with organising) support groups and information events. They meet on alternate months.

Fertility NZ is largely run on a volunteer basis, through the kindness of people wanting to support others through their fertility journeys. If you are interested in joining our lovely group of Christchurch volunteers, email support@fertilitynz.org.nz for more information.

The history of **public funding** of fertility treatment

Provision of publicly funded fertility treatment has been a long and winding road. New Zealanders still have a long way to go to reach the level of support seen in most countries in Northern Europe and in Australia.

Patient support groups have played a significant role in increasing the level of funding over the years, from the Auckland and Canterbury Infertility Societies in the early and mid 1980's to fertilityNZ (previously called the New Zealand Infertility Society) in the 1990's and 2000's.

This article charts the history of public funding to help understand the present situation, and why it is time to try for the next step in funding.

'Modern' fertility treatment started with interests of individual doctors, particularly an ovulation induction programme set up by 'Mont' Liggins (later Professor Sir Graham Liggins, after whom the Liggins Institute in Auckland is named) and a donor sperm programme set up by Professor Dennis Bonham. Both were at National Women's Hospital (NWH) in the late 1970's.

IVF started the same way when Dr Freddie Graham set up an IVF programme in 1983. After a stormy start with the Hospital Board wanting to close the fledgling unit, public support saw the Board change its mind. There was no specific funding, just people doing IVF as well as their other work. The equipment was shared, borrowed, donated or purchased with money raised by the Auckland Infertility Society. The IVF programme in Christchurch later started in a similar way, with funding from a community trust set up for the purpose.

Demand for IVF quickly grew, so that by 1986 the waiting list for IVF at NWH, at the time the only programme in the country, was equivalent to 7 years' workload. A 'loop hole' in the rules allowed the hospital to charge outpatients for drugs, which led to copayment by patients.

By the early 1990's the local hospital funding authorities had set their own guidelines. A review in the late 1990's showed annual funding for IVF varied between 25 and 75 cents per capita in different regions, the upper age limit for treatment varied between 36 and 38, the wait for IVF was typically 2-3 years, and only some areas offered non-IVF treatments such as IUI or donor insemination. Patients were offered 2-3 IVF cycles to become pregnant.

In 1994, the Core Services Committee of the Ministry of Health commissioned Professor Wayne Gillett of Otago Fertility Services and John Peek of Fertility Associates to investigate the cost and effectiveness of infertility treatments. This was followed by a request to come up with eligibility criteria for publicly funded treatment, which was the origin of the fertility CPAC (Clinical Priority Access Criteria) that is still used today. The CPAC was designed to give most points to those with a high chance of becoming pregnant with treatment, but unlikely to become pregnant by themselves. The report stated that it was impossible for the existing \$4.5 million currently being spent on fertility treatment to be fairly distributed – the amount was just too low.

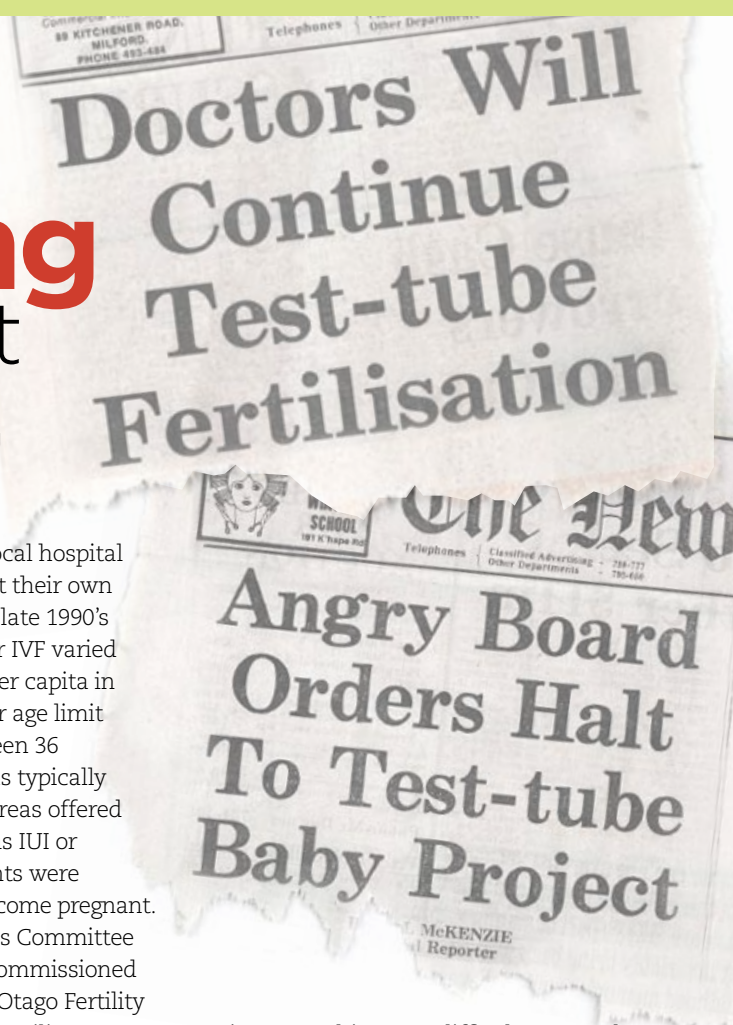
Around this time the government decided that people should get elective health services within 6 months of being enrolled, or not be eligible at all – long waiting lists were out! In Auckland during 1998, the Health Funding Authority provided an extra \$1 million to reduce the waiting list from 2-3 years to 6 months – the catch in the tail was that the 6 month wait had to be sustainable. The only way to do this was to reduce the number of IVF cycles per couple from 2-3

to just one. This was a difficult step, and the provider (Fertility Associates) asked those on the IVF waiting list to vote. The response rate was high, with the majority wanting the extra money in return for a short wait, even though it meant only one attempt at IVF.

Changes were also afoot nationally. Around 2000, the fertility CPAC was introduced with a threshold of 65, and funding was increased so that couples who scored 65 or more could receive one cycle of IVF (or a package of 4 cycles of IUI, donor insemination or ovulation induction) within 6 months of enrolment.

While welcoming equal funding over the whole country and a shorter waiting time, fNZ members were unhappy with only one cycle of IVF. fNZ launched its 'One is not enough' campaign.

At fNZ's annual conference in Wellington, both Labour's Annette King and National's Paul Hutchinson promised more funding. Labour won the election and fertility NZ pushed on, sending postcards to MPs and pushing empty strollers up and down the steps of Parliament buildings with placards stating 'Once is not enough'.



Annette King found money from her Minister of Health's discretionary fund, but it was insufficient. To help bridge the gap, the New Zealand IVF Directors, with fNZ support, proposed the additional funding be tied to single embryo transfer in younger women. At that time about 25% of IVF pregnancies were twins. It was calculated that single embryo transfer would save \$3 million annually in extra obstetric and neonatal care costs – which when added to the money provided by Annette King was sufficient to fund a second cycle for those not pregnant from the first.

The second cycle was announced in July 2004, and backdated to people having their first IVF cycle from July 2003.

By 2008, fNZ decided it was time to try again, and conceived its '3+ campaign'. The '3' covered:

- Up to 3 IVF cycles
- No more than 3 years waiting to become eligible
- 3% of children born from IVF, to match the level in Australia where funding was more generous.

The 'plus' covered:

- Increasing the upper age for eligibility from 39 to 42 – higher IVF pregnancy rates meant 42 year olds had the same chance of an IVF pregnancy as 39 years olds had when the CPAC was introduced
- Allowing people to try for a second child if they had not used all their 3 cycles
- Promoting fertility awareness and fertility fitness in the community

Unfortunately the campaign faltered as public health spending came under increasing pressure following the economic crisis at the end of the decade.

We are now trying again – the economy has improved and once again it is election year. Our approach is to:

- Ask consumers' about their priorities for extra funding, starting with series of focus groups followed by a survey of fNZ members
- Undertaking a cost-effectiveness study, as recently done in Australia, to show fertility treatment is an investment that is recouped in future taxes
- Finding advocates from all major parties to support the cause.

FOCUS GROUPS: Consumer priorities for fertility funding

Fertility New Zealand (FNZ) is conducting research about what consumers think about the fertility services currently available.

At Fertility NZ, we are interested in finding out what consumers of fertility services think are the most important things to be funded – especially if there was an increase in funding. For example, some possibilities could be:

- Loosening of existing restrictions such as:
 - funding of a third IVF cycle (instead of the current maximum: two)
 - age eligibility cut-off raised to 42 (from 40)
 - reduction in the waiting time for those experiencing unexplained fertility before funding becomes available
- Increased reimbursement of egg donor costs (currently \$300)
- Increased availability of other treatments

This information will be included in a Review of New Zealand Assisted Reproduction Technology (ART) Funding that will be prepared by the IVF Directors Group of New Zealand. As FNZ will shortly become involved in a campaign for increased funding (though there is no guarantee that an increase will occur), this research may have important implications for the future provision of fertility services.

It will provide an opportunity for you to have your voice heard, and for your opinion to be taken into consideration.

The first part of the research process will be group discussions, with 6–8 people – all consumers of fertility services. It is expected that each



discussion will take approximately 1½ hours, but this can vary.

We hope that a range of people will take part, so that a diverse range of opinions can be collected.

The information gathered will be used to construct a survey, which will be emailed out to all participants, as well as all FNZ Members, and other interest groups. The aim of this survey is to get wider participation and more concrete information, in numeric form, for example, to be able to answer questions such as "What percentage of consumers would like the age eligibility cut-off raised?" or "Is that considered more or less important than funding a third cycle?". The survey will probably be conducted in April or May.

Focus groups will be conducted in Auckland, Hamilton, Tauranga, Wellington and Christchurch during February.

If you are interested in taking part, contact Dr Cate Curtis, Researcher: ccurtis@waikato.ac.nz, 027 297 6804.



Premature Ovarian Failure

Nicole Evans shares her experience of Premature Ovarian Failure and tells how being part of a Support Group has given her strength, comfort and hope for the future.

I never could have dreamed my devastating experience of Premature Ovarian Failure at age 30 would end up being such a blessing. My husband and I went through 2 cycles of donor egg IVF that didn't result in the child we so wanted and for a long time I struggled to come to terms with that. It didn't seem fair that all my friends were starting their families while we were being left behind. But it seems our time of trial had a unique purpose.

I have been the National Co-ordinator of the New Zealand Early Menopause Support Group for 6 years now and the role gives me such a lot of satisfaction and fulfilment. Today, I am in contact with a fantastic group of about 100 women from around the country who all have such inspiring stories of courage and triumph to tell. I feel so privileged to be connected with other women on this journey, as I learn so much from them all. I am honoured to be a source of support to them at a time when the only person who can help is someone who has been down the same path. We are our own little community and it's incredibly important to me that it keeps going.

Premature Ovarian Failure (POF) is when the ovaries begin shutting down before the age of 40. It can even occur in teenagers. POF is surprisingly common, occurring in one or two in every 100 women under the age of 40, and one in every 1000 women under the age of 30. It is becoming more important as women delay having children until later in their lives.

Many women struggle to get a timely diagnosis of POF which delays their access to appropriate health care and fertility treatment if required. Sadly,

missed periods are a relatively common symptom, so this diagnosis can be quite low down on a doctor's list of potential concerns for a young woman. Many of our members have had to wait over a year for a diagnosis. The irony is two simple follicle stimulating hormone (FSH) and oestrogen level blood tests, done a month apart, are all that's needed to make this diagnosis.

So the support group does what it can to increase awareness and I think the best tool we have for making ourselves known to women who need us, and their doctors, is our website. On it is information about early menopause and what the support group offers our members, health information, and personal stories. This, along with our forum, provides New Zealand women with relevant information to help them make the best decisions for their long-term wellbeing.

There are many roads to a diagnosis of POF or Early Menopause. Cancer treatment, cancer surgery, and surgery for endometriosis can all damage, or result in the loss of, a woman's ovaries. For those with no external cause, there are some known immunological and genetic causes, but most of this latter group will never know why their periods stopped so young.

Regardless of cause, the resulting oestrogen-deplete state has a serious impact on long-term health and quality of life. From menopausal symptoms of hot flushes and brain fog, to the impact on bone health and sexual function, and loss of feminine identity, it's psychologically very challenging. And there's no one-size-fits-all approach to long-term healthcare as no two women seem to have the same experience or medical history, so it's important for



Premature Ovarian Failure is surprisingly common, occurring in one or two in every 100 women under the age of 40, and one in every 1000 women under the age of 30.

women to find a team of healthcare professionals experienced in premature menopause to help them through the quagmire of information – and misinformation – out there. There are many treatments available, some more effective than others, to help with symptom control, but there is as yet no scientifically proven treatment regime for women in our situation. Most are prescribed oestrogen to replace what is lacking in our bodies, but being on a drug for 20 or so years is a daunting prospect, especially one that has received such bad press as hormone replacement therapy has. Of course a good diet and exercise, and quitting smoking are all economical ways to help achieve long-term health goals.

One of the most devastating consequences of a diagnosis of POF or early menopause is the loss of fertility. About 5% of women with POF will get pregnant naturally, but, at present, the only reliable fertility treatment is

egg donation, whereby donor eggs are fertilised by the partner's sperm in a test tube and the embryos are implanted into the womb. But there is a shortage of donors in New Zealand. I think there are many reasons for this, but a large part of it is the lack of awareness of this procedure as an option, and the lack of adequate compensation for women who do want to donate. We are encouraged that Fertility NZ are launching a project in 2014 to lobby the government to better address the needs of the 20% of New Zealanders living with infertility.

When I was given my diagnosis I was told there was no way to make my ovaries start working again, and donor eggs were my only option to try to create my family. However, in October 2013 scientists announced the birth of a child from a new IVF technique 'In Vitro Activation'. This exciting development will mean that, one day, women diagnosed with POF will have the chance to have their own biological children. The procedure is still in its infancy, but we eagerly await the time it becomes available to all.

I've been amazed at how therapeutic it has been to be part of this group and to meet others facing similar issues. It totally removes the stigma I sometimes feel in my usual circle of friends and it is great to be able to learn from others. The first dinner I attended felt like the most liberating night of my life and I've never looked back! Of course we couldn't do what we do without the great work of the people and organisations we rely on; organisations like Fertility NZ, the Australasian Menopause Society, and international support groups, and the clinicians and researchers who are trying to make a difference. Together we create a network of resources and support that benefit us all.

For more information, please visit our website: www.earlymenopause.org.nz

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A Night with Jay-Jay Feeney

Although Dom Harvey didn't barge in to the room mid-talk dressed as 'supersperm' (those who attended the 2013 Information Day will remember this!), Jay-Jay managed to have her audiences in both laughter and tears at 'A Night with Jay-Jay Feeney'.

We held these sell-out events to celebrate the launch of Jay-Jay's book *Misconception* which tells the story (so far) of Jay-Jay and Dom's fertility journey. Jay-Jay recounted her story, true to form, with her trademark



humour as well as a few tear-jerkers! Drinks, nibbles, fantastic spot prizes and goody bags guaranteed that a good time was had by all. 'A Night with Jay-Jay Feeney' was held in Tauranga, Hamilton, Christchurch and Auckland. Following many requests from Wellingtonians, we tacked on an extra event in the Capital.

Thanks to all those who came along, and particularly to Jay-Jay for her ongoing commitment as Ambassador to Fertility NZ!



Share Your Journey

We need your help in an insightful new documentary series.

ScreenTime NZ in conjunction with NZ on Air and TVNZ is producing *Inconceivable*. This six part series will follow the journeys and share the stories and experiences of kiwis who are undergoing fertility treatment.

In New Zealand, 17% of Kiwis experience infertility issues and the impact on relationships, familial identity, finances, as well as physical and emotional pressures are far reaching. The goal of this documentary will be to raise awareness and understanding of infertility in New Zealand.

By sharing the stories of people on their fertility journey we aim to create an insightful, informative and emotionally compelling series. We encourage you to take part.

If you are interested in having a record of your own journey and being a part of this project or simply finding out more, please contact:

Nix Jaques at ScreenTime on 09 303 3339
or nix.jaques@screen-time.co.nz

Inconceivable: Quick Facts

Filming will begin in April 2014.

The series will be filmed over two years.

We are looking for a diverse range of people to be a part of this project.

ScreenTime New Zealand

ScreenTime is New Zealand's premier producer of drama, actuality, and documentary television. Since our first production in 1996 we have produced more than 1000 hours of high-end, award winning television programmes for all the major New Zealand television networks, and we have achieved considerable success abroad.

ScreenTime operates in New Zealand, Australia and Ireland. The group produces multi-award winning programmes in all genres worldwide. ScreenTime is part of the global production and distribution group Banijay International.

Inconceivable

noticeboard

Upcoming events

FEBRUARY

Sunday 2 February: Coffee Group, Gisborne
 Sunday 9 February: Support Group, Hawkes Bay
 Tuesday 18 February: Casual Coffee Group, Auckland
 Tuesdays 18, 25 February and 4 March: Contact Group, Auckland
 Saturday 22 February: Coffee and Chat, Wellington

MARCH

Sunday 2 March: Support Group, Gisborne
 Sunday 9 March: Support Group, Hawkes Bay
 Sunday 15 March: Secondary Infertility meet-up, Auckland
 Tuesday 18 March: Casual Coffee Group, Auckland

APRIL

Sunday 6 April: Support Group, Gisborne

Monday 7–Sunday 13 April: Fertility Week –
 check www.fertilityweek.org.nz for events!

Sunday 13 April: Support Group, Hawkes Bay
 Sunday 13 April: Secondary Infertility meet-up, Auckland
 Tuesday 15 April: Casual Coffee Group, Auckland

For more information, contact your local representative (see right) or email support@fertilitynz.org.nz

Local information

How can we help you in your area?

Fertility NZ Local Groups

Auckland

aucklandsupport@fertilitynz.org.nz
secondariesupport@fertilitynz.org.nz
 (secondary infertility)

Casual Coffee Group (Auckland)

casualcoffeegroup@gmail.com

Hamilton

hamiltonsupport@fertilitynz.org.nz

Tauranga

taurangasupport@fertilitynz.org.nz

Rotorua

rotoruasupport@fertilitynz.org.nz

Gisborne

gisbornesupport@fertilitynz.org.nz

Hawke's Bay

hawkesbaysupport@fertilitynz.org.nz

Wellington

wellingtonsupport@fertilitynz.org.nz

Christchurch

christchurchsupport@fertilitynz.org.nz

Gisborne Support Group

Gisborne has a new support group which meets around once per month on the weekend. Catch-ups are very casual and based on support, laughter and sharing information and experiences. We welcome new couples! If you would like to come along, or just want a chat, call Ana on 021 2136610 or email gisbornesupport@fertilitynz.org.nz

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fertility
NEW ZEALAND